

**Improving the health and wellbeing of people  
who are not benefiting from long-term opioid  
substitute treatment**

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## Abstract

In the UK, opioid substitute treatment (OST) is an important intervention that is used to treat heroin or illicit opioid dependency. Research has shown that OST is highly beneficial for both individuals who are struggling with their heroin use and society. However, there is growing recognition that there is a significant proportion of long-term OST patients with complex needs who are struggling to achieve benefits from treatment. Relatively little is known about the reasons why this is the case. The research presented in this thesis aimed to fill this gap in knowledge by improving understanding of the barriers to success faced by this cohort and how these barriers can be overcome to improve the health and wellbeing of OST patients. To achieve these aims, a qualitative study was conducted that involved: 1) in-depth interviews with 38 OST patients who had been engaged with OST for five years or more on a continuous or intermittent basis, 2) in-depth interviews with 20 staff members who had direct experience of working with the above-mentioned population, and 3) a ‘microethnography’ of a busy drug treatment service operating across South Wales.

This is the first time that Zinberg’s (1984) *drug, set and setting* theoretical framework has been used in the exploration of barriers to treatment success in the long-term OST population and how these barriers can be addressed by treatment services. The findings show that *drug, set* and *setting* barriers interact in complex ways to affect the health and wellbeing of the OST patient. The lack of appropriate support to address the complex needs of the OST patient, the failure of treatment services to provide adequate time that meets the complex needs of OST patients, the absence of opportunities for integration within treatment services, the failure of treatment services to provide an individualised approach and the negative impact of treatment rules/regulations on OST patients’ lives are important barriers that affect the wellbeing of the OST patient. The provision of appropriate support that meets the complex needs of OST patients and reintegration opportunities with society could help to promote progression in treatment. Additionally, the administration of Buvidal (depot form OST) and the adoption of an individualised approach could help to meet the diverse needs of the OST population. The findings of this study have important implications for treatment services, drug policy, legislation and harm reduction.

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## **CHAPTER ONE – Introduction**

This study focusses on the identification of barriers faced by the long-term opioid substitute treatment (OST) population in achieving benefits from OST and how these barriers could be addressed by treatment agencies to improve the health and wellbeing of the OST patient. The study involved interviews with the long-term OST population who have been engaged with OST for a period of five years or more on a continuous or intermittent basis. The study also involved interviews with staff members who have direct experience of working with the above-mentioned OST population. Field notes were also collected as part of the ‘microethnography’ which involved observations at dispensing sites, the Hub and informal Hot Dog mornings at a busy drug agency in South Wales. This chapter describes the background of this research, the research context, the research focus and approach, the research questions, a brief description of the methodology and ends with an outline of the structure of the thesis.

### **1.1 Background**

Heroin is an opioid. Opioids are a category of drugs which include compounds that are derived wholly or partially from the opium poppy and includes synthetic derivatives that imitate the effects of opiates (National Institute on Drug Abuse (NIDA), 2021). Approximately 62 million individuals across the world were estimated to have used opioids in 2019 (UNODC, 2021). When heroin is used on a prolonged basis and stopped, unpleasant withdrawal symptoms may occur (NIDA, 2017). Some people are fortunate enough to use heroin in a controlled manner with minimal impact on their everyday lives (Warburton, Turnbull and Hough, 2002). However, some people who use heroin may become ‘addicted’ or physically and psychologically dependent (Maddux and Desmon, 2000). Some people are able to overcome dependency without the assistance of formal treatment (Granfield and Cloud, 1996). Others, however, may need the external support to help overcome their dependency on heroin.

In the UK, opioid substitute treatment (OST) is an important intervention that is used to treat dependency on heroin or illicit opioid dependency (Public Health England (PHE), 2021). OST is comprised of two components, which are: pharmacological and psychosocial elements (PHE, 2021). The pharmacological element involves the substitution of the use of illicit opioids with

prescribed opioids such as methadone or buprenorphine (PHE, 2021). These medications reduce or stop withdrawal symptoms and relieve cravings, without the generation of highs associated with heroin (PHE, 2021). At the optimal dose, substitute medication can block the ‘high’ of heroin (PHE, 2021). The psychosocial element (also known as the ‘talking’ element) helps with stabilisation on the substitute medication and the initiation of positive lifestyle changes, to help overcome dependency on heroin (PHE, 2021). There is an extensive evidence base, which shows that OST is highly beneficial in reducing: the spread of blood borne viruses such as HIV, heroin use, risky sexual behaviours, the risk of overdose, drug-related deaths, complications for pregnant women and offending behaviour (World Health Organization (WHO), 2004; European Monitoring Centre for Drugs and Drug Addiction (EMCCDA), 2021).

Yet, despite these positive outcomes, research has shown that there is a small cohort of OST patients who are struggling to achieve benefits from treatment, despite long-term engagement. In the UK, there is also growing recognition of a cohort of long-term ageing OST patients with complex physical and mental health issues who are struggling to achieve benefits from OST (Advisory Council on the Misuse of Drugs (ACMD), 2019). However, research has shown that poor outcomes are not confined to older people and the ageing process but extends to the younger population of OST patients too (Metrebian et al. 2015).

### ***1.1.1 Terminology***

People who are not achieving benefits from OST have been described in the literature as ‘hard to treat’, ‘hard to reach’, or ‘treatment resistant’ (Metrebian et al. 2015). The Scottish Drugs Forum (2020) suggests that terms such as these should be avoided because they imply that the problem is due to the characteristics of the individual patient rather than the treatment system. Labelling people in this way is counterproductive as it can lead to negative stereotypes, stigma and can therefore serve to perpetuate behaviours consistent with that label (Bernburg, 2009). Labelling theory is particularly relevant to drug using behaviour, given the high levels of “social ostracism” involved (Szwejkka, 2013; p.343). Application of labelling theory suggests that labelling long-term OST patients as ‘treatment resistant’, can perpetuate behaviours that are consistent with that label. Given that the long-term OST population is already exposed to multiple stigmas associated with ageing, drug use and being on a ‘script’ (Connor and Rosen,

2008), I have avoided using the potentially stigmatising label of ‘treatment resistance’ throughout this thesis (Conner and Rosen, 2008).

## **1.2 Research focus and approach**

There is growing recognition that there is a cohort of long-term OST who are not achieving benefits from treatment (ACMD, 2019, Dame Carol Black, 2021; HM Government 2017). Despite this recognition, little is known about the reasons why these patients are struggling to achieve benefits from treatment. The research on which this thesis is based seeks to help fill this important gap in knowledge. Ultimately, the goal is to help find ways of improving the health and wellbeing of patients who are struggling to achieve success in OST. The research focused on a busy drug agency operating across a region of South Wales. This focus on Wales is of particular importance, given that few studies have been conducted in the UK and none, to the best of my knowledge, have included patients living in Wales. Indeed, most studies that have explored the barriers faced by the long-term OST population have been conducted in Ireland or England (Moran et al. 2018, Notley et al. 2015; Dennis, 2021). This gap is notable given the different political stances of the UK and Welsh Government on substance misuse (see Chapter three). This thesis is focussed on improving the health and wellbeing of long-term OST patients. It is therefore directly relevant to the Wellbeing of Future Generations (Wales) Act 2015 which strives to improve the a) social, cultural and economic wellbeing of Wales and b) achievement of wellbeing goals such as a healthier Wales, a more equal Wales, a Wales of cohesive communities and a prosperous Wales.

To date, most research has focussed on the exploration of barriers to success faced by the long-term OST population who have been engaged with OST for five years or more on a continuous basis (Notley et al. 2013; Notley et al. 2015; Moran et al. 2018). This means that there is an absence of research on patients who have been engaged with OST on an intermittent basis. This omission is important, because of the increased risk of overdose at the termination of treatment episodes (Prenoxad Injection, 2019). To address this gap, the research presented in this study therefore included patients who had been in OST either continuously or intermittently for at least a five-year period.

Previous research has compared the perspectives of OST patients and staff members on abstinence and recovery (Notley et al. 2015). However, there is little research that has directly

compared the perspectives of staff members and OST patients on: a) the barriers faced by the long-term OST population in achieving benefits from treatment, and b) the potential solutions that could help to improve the health and wellbeing of OST patients who are struggling to achieve benefits from treatment. To fill this gap in knowledge, this thesis also includes interviews with staff members which will provide different perspectives on barriers experienced by the long-term OST population.

While most research on barriers in relation to the long-term OST population has focused on OST patients who are prescribed methadone, there is relatively little research that has focused on the barriers faced by the long-term buprenorphine population. This is of particular relevance given the varying effects of substitute medication and different methods of diversion that are possible with the different forms of OST. To address this gap, this thesis will include OST patients who have been prescribed buprenorphine. This thesis also involved interviews with long-term OST patients who have been prescribed prolonged release buprenorphine (Buvidal) which is a relatively under researched area.

Lastly, while Zinberg's (1984) *drug, set and setting* framework has been used to explore overdoses within the heroin using population (Ataints et al.2020; Lamonica et al. 2021), to the best of my knowledge, this is the first piece of research that has used the framework to explore barriers to treatment success and potential solutions among the long-term OST population.

This study therefore provides a unique contribution to knowledge through its: novel application of Zinberg's (1984) framework, focus on Wales, inclusion of staff and patients, inclusion of patients on different kinds of OST including injectable buprenorphine, and the inclusion of patients who have been on OST intermittently or continuously over a five-year period.

### **1.3 Research aims and questions**

The overarching aims of this study are to improve understanding of the barriers faced by the long-term OST population that hinder their progress in OST and to identify ways in which these barriers could be addressed and overcome.

More specifically, this project seeks to address the following research questions:

- 1) What are the barriers faced by the long-term OST population that prevent them from achieving benefits from this type of treatment?
- 2) How do these barriers prevent the long-term OST population from achieving benefits from OST?
- 3) What are the solutions to overcome the barriers (faced by the long-term population) that prevent achievement of benefits from OST?
- 4) How can treatment services address these barriers to improve the health and wellbeing of the OST patient?

#### **1.4 Research methods**

To achieve the above-mentioned aims, the following qualitative research methods were used:

- 1) Interviews with the long-term OST population who have been engaged with OST for five years or more on a continuous or intermittent basis.
- 2) Interviews with staff members who have direct experience of working with the long-term OST population.
- 3) A microethnography of drug treatment services in South Wales that included informal visits to the various sites in which the drug service operates.

The decision to define 'long-term' engagement in treatment as five years or more was based on the use of this definition in previous research with this population (Notley et al., 2013). (Notley et al. 2013). The definition of 'long-term' treatment was discussed both with individuals with lived experience and Sian Chicken (Director of Drug agency) and it was agreed that 'five years' was appropriate to describe the long-term OST population. While Notley et al. (2013) focused on patients who had been engaged continuously for five years, it was agreed that it would be more useful to also include patients who had been engaged intermittently over that period. It was felt that this more inclusive approach would allow for different views of OST patients who have been engaged with OST patients on an intermittent

basis. This is particularly important given the high incidence of overdose at the termination of treatment episodes (Prenoxad Injection, 2019).

A qualitative research strategy was used because of its usefulness in capturing detailed accounts of memorable experiences that are personal and relevant to participants' lives (Khozbi et al. 2009). Furthermore, most research that has sought to improve the wellbeing of long-term OST patients has been quantitative in strategy and has involved correlating characteristics of users with key outcomes (Metrebian et al., 2015). Therefore, it was believed that the use of a qualitative strategy would add a new perspective to the existing literature on this topic and help to fill an important gap in knowledge.

### **1.5 Structure of thesis**

Chapter One has provided contextual information and outlined the research aims and objectives.

Chapter Two moves on to explain why some people become dependent on heroin and need professional support to cope with their substance misuse problems. In so doing, the chapter provides background contextual information about heroin including its origins, the way it is produced, routes of administration and the effects it has on the user. The chapter also considers the different ways of estimating the prevalence of heroin use in the UK. Within the chapter, Zinberg's (1984) framework is presented and used to identify the drug, set and setting factors that motivate people to use heroin. The chapter reflects on the harms associated with heroin use and considers various methods of reducing those harms. Towards the end of the chapter, the concept of OST is introduced as an important method of reducing harm.

Chapter Three provides detailed information on OST. This chapter commences with a description of OST which is followed by a review of the history of OST. The chapter explores the underlying philosophies of OST as well as the delivery of OST, with a particular emphasis on how it operates in Wales. The effectiveness of OST is examined drawing on the findings of systematic reviews of studies that have evaluated OST.

Chapter Four explores the literature on what is known (and what is unknown) about why some long-term OST patients fail to achieve benefits from treatment. To help structure the findings, Zinberg's (1984) theoretical framework was used to present *drug, set and setting* barriers and the solutions to treatment success.

Chapter Five provides a detailed description of the methodology that was used in this thesis. This chapter presents research questions and information on how I gained access to participants. The chapter also describes the different modes (face to face, online and telephone) of interviews that were used to collect the data on which this thesis is based. The sampling procedure is also presented, along with a discussion of how co-production was used to guide the study at all stages. Information is also provided about the approach used to conduct the data analysis. The chapter ends with discussions surrounding the ethical issues and limitations of the study.

Chapter Six, Seven and Eight present the results of this thesis (i.e. the barriers and potential solutions to these barriers). Zinberg's (1984) framework is used to categorise the barriers as either *drug, set* or *setting*-related factors. Chapter Six explores the *drug* barriers identified by the participants that could prevent achievement of benefits from treatment. Chapter seven and eight presents *set* and *setting* barriers, respectively, that could affect achievement of benefits from treatment.

Chapter Nine reflects on the findings as a whole in relation to the existing literature. This chapter discusses in detail how the *drug, set* and *setting* barriers prevent success in treatment and considers how the potential ways in which these barriers could be addressed, sit with existing literature.

Chapter Ten is the Conclusion. This final chapter summarises the findings and includes a reflection of the impact of the study on my personal development. The chapter then moves on to discuss implications for policy, practice and future research.

Recent statistics show that the number of deaths among people with a history of drug treatment are steadily increasing in Wales. In 2014-2015, 37 drug treatment episodes were closed due to death (the cause of death was not reported), while in 2018-2019, 65 drug treatment episodes were closed due to death (Welsh Government, 2019). While the data source refers to ‘episodes’ it is important to remember that each one of these episodes relates to the death of a human being; son, daughter, friend or relative. Clearly, something needs to be done to reverse the upward trend of deaths among people in treatment and to help patients achieve positive health and social outcomes.

This chapter has introduced the reader to this thesis, by providing a description of the background and aims of the study. The next chapter will present detailed information on heroin and explain why some people become dependent on the drug.

## CHAPTER TWO – Heroin dependency

### Introduction

Heroin is an opioid. Opioids are a broad category of drugs that include compounds extracted either wholly or in part from the opium poppy (often referred to as opiates) as well as synthetic alternatives that mimic the effects of opiates (National Institute on Drug Abuse (NIDA), 2021). Approximately 62 million individuals across the world were estimated to have used opioids in 2019 (UNODC, 2021). This is almost double the number of people estimated to have used opioids in 2010 (UNODC, 2021). This large increase has been attributed, at least in part, to the increased availability of these drugs in Asia and Africa (UNODC, 2021).

The aim of this chapter is to provide a detailed understanding of what heroin is and why some people who use it become dependent and need professional support and treatment. Given this broad aim, the chapter covers a wide range of issues including where heroin is produced, how it is produced, what heroin looks like, how it is administered, and what effects it has on the people who use it. Particular attention is given to the reasons why people use heroin and Zinberg's (1984) *drug, set and setting* framework is used to explore the role of the drug, the mindset of the user and the context in which the drug is used in motivating people to use heroin. The chapter also explores the harms associated with heroin use and the methods used to minimise these harms, most notably opioid substitute treatment (OST). The chapter is an important part of the thesis as it introduces and explains key concepts that are examined and discussed in later chapters.

### 2.1 Opium cultivation

The opium poppy is part of the poppy family (*Papaveraceae*) and is a “species of the genus *Papaver*” (Encyclopedia Britannica (EB), 2017). As seen in Fig.1, the poppy plant grows to heights ranging from three to sixteen feet with blue-purple, white or red flowers (EB, 2017).

Fig.1 The opium poppy (EB, 2017)



“Raw opium gum” is derived from the capsule of the poppy plant after the petals of the opium flower have withered (Ashton, 2002). Painkillers such as morphine, heroin and codeine are derived from the “milky sap of the opium poppy- *Papaver somniferum*” (Ashton, 2002, p.57). The painkilling properties of the opium poppy were attributed to fusion of two genes, which it is estimated could have occurred 7.8 million years ago (Nemo, 2018). This fusion resulted in the formation of a ‘megagene’, which is associated with the production of codeine and morphine. There is also scope for genetic modifications “to make the poppies produce more of the pharmaceutical agents, grow faster or withstand infections” (Nemo, 2018).

There has been a trend of increased cultivation of the opium poppy since 2019 (United Nations Office on Drugs and Crime (UNODOC), 2021). In 2021, the cultivation of the opium poppy increased by 24% to 295,000 hectares (ha) in comparison with the previous year (UNODOC, 2021). This rise can be attributed to the raised levels of opium poppy cultivation by 37% in Afghanistan (UNODOC, 2021). The production of opium in Afghanistan, Mexico and Myanmar accounts for approximately 96% of the global opium production. Afghanistan represents 85% of the global opium production (UNODOC, 2021).

### **2.1.1 Pharmacological properties of opium**

The pharmacological effects of opium can be attributed to its alkaloids. The six alkaloids that occur in the largest amounts in opium are: morphine, codeine, narcotine, narceine, papaverine and thebaine. Three of these (morphine, codeine and thebaine) are under international control and all three are used in the drug industry (UNODOC, 1953). Morphine is the primary alkaloid of opium and normal unadulterated opium normally has 8-19% of morphine (UNODOC, 1953). The content of codeine is associated with the variety of opium produced in a country (UNODOC, 1953). Out of all the alkaloids, thebaine is the most poisonous alkaloid (UNODOC, 1953). Papaverine is commonly used for medical reasons and is manufactured synthetically too to meet the demand (UNODOC, 1953).

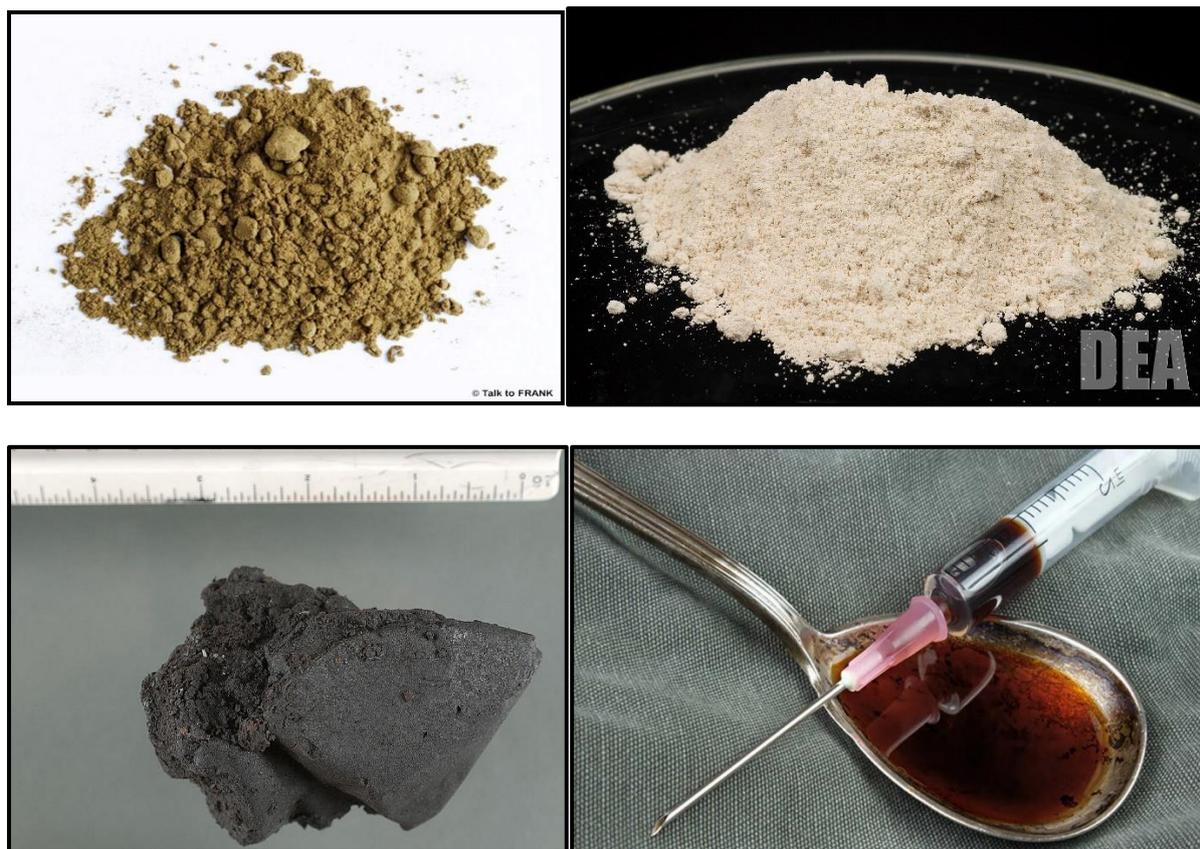
When an opioid enters the body, it generates a painkilling effect by attaching to specific receptors that are normally the sites for endorphins. These mu opioid receptors are present in the central nervous system, the stomach and intestines (Release, 2022). Persistent use of opioids will result in the formation of more mu opioid receptors, which are different to the original receptors in that they will 'receive' opioids but not endorphins (Release, 2022). This alteration in receptors can result in the user of opioids experiencing more negative feelings than they had experienced before first using them (Release, 2022). These negative feelings are understood to encourage persistent use of opioids as users seek a return to their original, less negative, mood state or to relive the 'first time' effects of opium.

Substances such as heroin and morphine that are derived either wholly or in part from the opium poppy are a type of opioid known as 'opiates'. Substances such as methadone and fentanyl that are derived wholly from non-natural matter are referred to as 'opioids' but not 'opiates' (United States of America. Oregon Alcohol and Drug Policy Commission (OADPC) 2018). Heroin is known as a semi-synthetic opiate because it is produced from natural opioids and synthetic derivatives in a laboratory (Barrell, 2021). The global opium production of 7,140 tons in 2020 is enough to produce 454-694 tons of heroin (UNODOC, 2021). The transformation of opium into heroin is a prolonged and sophisticated process. This process usually happens in a laboratory, where various additives are added at high temperatures (Ashton, 2002).

## 2.2 Appearance and smell of heroin

Heroin is also known as diamorphine, as it is derived from morphine (National Institute on Drug Abuse (NIDA), 2018). Heroin has been described as a “narcotic analgesic used in the treatment of severe pain” (European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), 2015). Heroin is usually in powder form and can be brown, white, “a black sticky substance known as tar heroin”, or in the form of a liquid as seen in Fig.2 (NIDA 2018; United States Drug Enforcement Administration, 2021). The colour of heroin may be dependent on the country of origin: heroin originating from Southeast Asia is normally white, heroin from Southwest Asia is usually brown and Colombian heroin is white-light brown (Ciccarone, 2009). Mexican heroin is normally dark-brown to black in colour – hence the name ‘black tar heroin’ (Ciccarone, 2009).

*Fig.2 Heroin (FRANK, 2018; National Institute on Drug Abuse 2021; Wikipedia, 2022; Addiction Resource, 2022)*



Heroin “emits acetic odor on prolonged exposure to air” and its taste is usually bitter (U.S. National Library of Medicine, 2018). The characteristics of heroin may also vary by country

of origin, as Southeast Asian heroin has high water solubility and acidity, while Southwest Asian heroin has lower levels of water solubility and strong heat stability (Ciccarone, 2009). Mexican heroin is solid, can be vapourised and usually has lower levels of purity than heroin originating from other parts of the world (Ciccarone, 2009).

There are clearly different forms of heroin, but the real value of the drug is dependent on the amount purchased, the price of the drug and purity of the drug (Caulkins, 2007). The illegal heroin used by many individuals around the world has various levels of potency, ranging between 0.1% and 95% (UNODOC, 2021). The potency of heroin depends on the production process, but it may also be dependent on the type of cutting agent used by those selling it to consumers. For instance, caffeine enhances the strength of the drug while glucose, paracetamol, lactose and strychnine weaken the effects of heroin (Ashton, 2002).

### ***2.2.1 Purity of heroin***

The purity of heroin in England and Wales has increased consistently since 2011, with an average purity of 46% in 2018 (Focal Point, 2021). There are several possible explanations for this increase in purity. First, it may be due to the increase in the global supply of heroin (Focal Point, 2021). Alternatively, it has been suggested that dealers have tried to sell ‘strong purity’ heroin to attract customers, especially given the fall in the number of people who use heroin in recent years (Drugwise, 2017). Finally, the increased purity could be attributed to the desire of dealers to avoid unwarranted attention involved in the trafficking of adulterants, such as fentanyl, carfentanyl, caffeine and paracetamol (Drugwise, 2017; Sunderland, LPC, 2022; Broseus et al. 2016).

Purity determines the effect on the body. The purer the heroin the stronger the effect and the more opioid will be found in the blood. Research has found that when purity is low, it leaves the body more rapidly, which leads users to experience more frequent and rapid withdrawal symptoms (Trafton, Minkel and Humphreys, 2006). As a result, users of low purity heroin can sometimes require more intensive support and treatment to help them cope.

When people use heroin with a high level of purity, there is an increased risk of overdose. One explanation for this is that the potency is more than the user's tolerance to the drug (Darke and Hall, 2003). So, what does tolerance actually mean? Briefly, increased tolerance happens with repeated use of heroin because more quantities of the drug are needed to achieve the same effect on the body (NIDA, 2017). Over time with repeated use, the body adapts to the effect of the drug meaning that more is needed for the same initial effect to be achieved.

In light of this, the fact that many fatal overdoses occur among people with long histories of heroin use is puzzling (ONS, 2021). One might expect that a long history of heroin use would result in a high level of tolerance that would protect users from overdosing on heroin with a high level of purity. Darke and Hall (2003) reviewed the literature to explore the issue and found that long-term users of heroin do not always consume heroin at the same rate and that their tolerance levels fluctuate over time depending on their level of use. Research has found that the risk of overdose is elevated among people in the period immediately following their release from prison and in the period after being discharged from treatment (Merrall et al. 2010; Prenoxad Injection, 2019). Both are periods when the use of heroin is likely to have been lower and tolerance has dropped (Darke and Hall, 2003). The use of depressants such as alcohol and benzodiazepines have also been linked to an elevated risk of overdose (Darke and Hall, 2003). This implies that purity alone is not the cause of overdose but that other factors such as polydrug use and periods of abstinence are contributory factors.

To summarise, the relationship between purity of heroin and overdose is not straightforward. Contrary to the expectation that long-term users of heroin have increased tolerance levels and therefore protection against overdose, statistics show a high incidence of long-term heroin users within the fatal overdose population. This suggests that long-term users of heroin are not immune to overdose and still need advice and support to keep them safe and alive.

### ***2.2.2 Price of heroin***

It is difficult to ascertain the accurate price of heroin because self-reports of heroin users are based on guesses of quantity and expectations of purity (Caulkins, 2007). However, the data suggests that in 2017, the street price of 0.1 gram of heroin was £10 in South Wales (Drugwise,

2017; Health, Social Care and Sport Committee, 2018). This price of £10 is consistent across the UK and has remained fairly consistent over time (Drugwise, 2017; UNODOC, 2019).

Hughes, Hulme and Ritter (2020) reviewed 36 studies to examine the impact of purity and harm to the population. They found that drug potency interacts with availability and price in complex ways. For instance, during periods of low availability, prices increased and potency decreased. They also found that high purity-adjusted prices (PAP) were related with a decline in emergency department admissions (Hughes et al. 2020). This was because purity levels had dropped leading to fewer overdoses that required hospital admission (Hughes et al. 2020).

Drugs can be considered to be “experience goods” because the quality of the drug is unknown prior to the exchange of money (Caulkins, 2007). In an illicit market there are no guarantees that the buyer is going to get good value for money because the quality of the drug is unknown prior to the exchange of money (Caulkins, 2007). This means that there is always the chance that buyers will be disappointed with the quality of drug purchased. With no legal recourse in an illicit market, dealers are free to market their wares anyway they like (e.g. claim they are high quality when they are not) (Caulkins, 2007). Nevertheless, buyers are often desperate and will buy whatever is available in anticipation of the positive effects experienced previously.

### ***2.2.3 Effects of heroin***

The effects of heroin vary hugely depending on a multitude of factors including: its purity (i.e. whether it has been adulterated with cutting agents), the nature of any cutting agents, how it is administered, and how much is used. Depending on these factors, serious harm can be caused to the user. Indeed, the harms of heroin use are commonly related to “contaminated injecting equipment or impure supplies of the drug” (Carnwath and Smith, 2002, p.139). By contrast, the use of pure (pharmaceutical) heroin (also known as diamorphine) in a controlled environment is far less harmful and research suggests that in its pure form heroin does no harm to the body.

Polydrug use is common among the heroin using population (Darke and Hall, 1995). Polydrug use can be described as “the use of more than one substance (legal or illegal) consumed at the same time or sequentially” (Pycroft, 2015; p.52). A significant proportion of people who use heroin also use tobacco, cocaine, and cannabis (i.e., they are polydrug users), and their lives are characterised by poor eating patterns during periods of heroin consumption (Pitt et al. 2015; Neale et al. 2011). Assessing the independent effects of heroin on users is complicated by the confounding effects of other drugs as well as the chaotic lifestyles of many heroin users, which are in themselves associated with a wide range of harms.

When heroin is used, it travels to the brain and is altered into morphine, which then swiftly attaches to opioid receptors (NIDA, 2018). Normally, physiological defences prevent the entry of substances from the blood to the brain (Carnwath and Smith, 2002). However, the high fat solubility of heroin means that it passes into the brain easily (Carnwath and Smith, 2002). This high concentration of heroin in the brain generates the flood of immensely pleasant sensations including a ‘rush’ that is favoured by many users of heroin (Carnwath and Smith, 2002). The power of this warm feeling is dependent on the quantity used and the speed with which heroin floods into the brain and attaches to opioid receptors. Heroin can also stop pain messages conveyed through the spinal cord from the body (NIIDA, 2018). High levels of heroin consumption are associated with drowsiness and at extremely high levels with unconsciousness (Ashton, 2002).

Use of heroin may also cause “a warm flushing of the skin, dry mouth and a heavy feeling in the extremities” as well as nausea, vomiting and itchiness (NIDA, 2018, p.5). The neurochemical activity in the brain stem, where functions such as breathing and hearing rate are controlled, is altered by the use of heroin (NIDA, 2018). This alteration means that breathing can be depressed by the use of heroin and this could lead to coma, permanent brain damage or even death (NIDA, 2018). The initial stages of heroin use are also related with pale skin complexion and loss of weight (Ashton, 2002). Even the first use of heroin has been related with development of rhabdomyolysis (“a complex medical condition involving the dissolution of damage or injured skeletal muscle”) and kidney failure (Gupta et al. 2011; Torres, et al.p.58).

The effects of heroin are not confined to the short term as heroin consumption is related with constipation, malnutrition, and poor oral health if use is sustained over a longer period of time (Ashton, 2002; Mehmood et al. 2018). Heroin intoxication is also related with enhanced risk of development of non-cardiogenic pulmonary oedema, which can lead to a deficiency in oxygen levels and have an adverse impact on respiration levels (Osterwalder, 1995; Megarbane and Chevillard, 2013; Clark and Soos, 2021).

Research has shown that the effects of heroin on the body depend on the route of administration. For instance, the inhalation (or smoking) of heroin is related with an increased risk of heroin-induced leukoencephalopathy (adverse impact on white matter of the brain), in comparison to other routes of administration (Alshamam et al. 2021). Similarly, harm to veins, skin and soft tissue infections can result from the injection of heroin (Harris et al. 2019).

### **2.3 Route of administration**

Heroin can be administered in a number of different ways. It can be snorted, smoked, injected, eaten or stuffed in the rectum (Harm Reduction Coalition (HRC), 2001). This section will examine the different routes of administration and review the risks associated with each route. It will also consider the harm reduction measures that could alleviate the risks and different factors that could influence the choice of route of administration.

#### **2.3.1 Smoking**

Smoking heroin first started in Shanghai in the 1920's and involved the use of porcelain bowls and bamboo tubes (Strang, Griffiths and Gossop, 1997). 'Chasing the dragon' is a modification of this smoking process, which involves the heating of heroin on aluminium foil to initiate the vaporisation process (Strang et al. 1997; HRC, 2001; Fig.3). The vapours are then inhaled through a straw, pipe or tube (HRC, 2001).

*Fig.3 Smoking heroin (The Independent, 2014)*



Smoking is associated with a risk of asthma, damage to lungs but with a low risk of hepatitis. This is because there are no needles involved in this route of administration and hepatitis is normally transmitted through the sharing of needles (US Department of Health and Human Services, 2016). Most types of heroin are either heroin base or heroin hydrochloride (Carnwath and Smith, 2002). Heroin base is pure diamorphine, while heroin hydrochloride is a diamorphine salt, which is produced by reacting diamorphine with hydrochloric acid (Carnwath and Smith, 2002). Heroin base is more unstable and has a lower melting point than heroin hydrochloride (Carnwath and Smith, 2002). This means that it is more appropriate for smoking in comparison with heroin hydrochloride (Carnwath and Smith, 2002). However, the addition of barbiturates and caffeine enhances the smoking potential of heroin hydrochloride (Carnwath and Smith, 2002).

With the practice of smoking heroin, it is inevitable that some heroin will get lost to the air. The incorrect practice of smoking could further increase the amount of heroin lost (Carnwath and Smith, 2002). Skilled movement of the foil and tube and application of heat at the right temperature has been found to reduce wastage of heroin, although this involves great skill and dexterity (Carnwath and Smith, 2002).

In 2014, The Misuse of Drugs Regulations was amended to allow treatment services to provide foil legally to people who use heroin. This specialist foil is thicker, more durable and reduces the wastage of heroin when smoking (Home Office, 2016). It was hoped that this provision of

foil would encourage more users of heroin to smoke instead of injecting the drug (Home Office, 2016). This desire to encourage a switch to smoking is based on the premise that injecting is associated with serious risk of harm including the transmission of blood borne viruses, infections and vein collapse (Home Office, 2016).

### **2.3.2 Injecting**

Injecting is the administration of a drug through a needle and syringe into a vein (intravenously), into a muscle (intramuscularly) or beneath the skin (subcutaneously) (Public Health Scotland, 2021). Citric acid or Vitamin C is heated with brown heroin with a lighter or gas stove, to help with the dissolution process injection as heroin base is not very soluble in water (Harris et al. 2019; National Harm Reduction Coalition, 2021; Fig.4). After the drug is ‘cooked’, the solution is drawn through a syringe with cotton, and the syringe is tapped to remove air bubbles. People who inject may use tourniquets or ties to reduce blood flow and increase accessibility of veins for injecting (National Harm Reduction Coalition, 2021).

*Fig.4 Preparation of heroin for injection (Addiction Resource, 2022)*



Research has shown that injecting intravenously is the riskiest route of administration. Injecting heroin users are at an increased risk of overdose and drug-related death (Public Health Scotland, 2021). The relation between injecting and increased risk of overdose could be explained by the fast delivery of the drug into the bloodstream, rapid onset of the effects of the drug, increased severity of the effects and the inability of the individual to assess the quantity/strength of the drug (Lesser, 2021; Informal communication with clinical staff at Drug agency, 2018; Mars, Ondoscin and Ciccarone, 2018).

Injecting is also associated with a range of other harms. For instance, the spore-forming bacteria in the environment has been found to contaminate drugs and result in bacterial infections such as botulism, tetanus and anthrax (UK Health Security Agency, 2021). Repeated injections are associated with venous sclerosis (scarring), which can stop them from functioning properly, and with deep venous thrombosis (Ciccarone and Harris, 2012). Injection of drugs is also associated with skin and soft tissue infections such as abscesses and cellulitis and in worst circumstances, amputation of limbs (Ciccarone and Harris, 2012). Damage to veins is more likely if injecting is frequent and if the user is injecting into their femoral vein (commonly called groin injecting) or subcutaneously (under the skin) (Harris et al. 2019). Injecting into the femoral vein in the groin is dangerous because it is associated with leg ulcers and vascular insufficiency (Maliphant and Scott, 2005). The close proximity of the femoral vein to the artery also means that there is an enhanced risk of trauma at this site (Maliphant and Scott, 2005). Subcutaneous injection of ‘black tar heroin’ is associated with wound botulism (National Harm Reduction Coalition (NHRC), 2020). The condition of wound botulism is triggered by bacteria that generates a toxin on the skin at the site of the puncture wound (NHRC, 2020). Wound botulism can result in the stopping of breathing and paralysis of muscles (NHRC, 2020). Wound botulism was diagnosed in an individual who injected heroin subcutaneously at Royal Gwent Hospital in Newport, South Wales (Sloan, Coupe and Gough, 2002).

The sharing of injecting equipment is associated with the transmission of blood borne viruses such as Hepatitis and HIV (Centers for Disease Control and Prevention, 2021). This risk can be attributed to the presence of blood in injecting equipment, which could transmit HIV (Centers for Disease Control and Prevention, 2021). Despite these immense risks, injecting is popular among heroin users. This is due in part to the absence of wastage as the heroin goes straight into the body without any being lost to the air. The “instant high, along with a rush” have also been described as important motivating factors for heroin users to choose this method (Carnwath and Smith, 2002; Rosenbaum, 1979). However, the lower risk of infection and the absence of the need for additional injecting equipment makes the snorting of heroin a more attractive option for some users of heroin (Cone et al. 1993).

### **2.3.3 Snorting**

Brown base heroin is normally dissolved with Vitamin C or citric acid prior to the snorting process (HRC, 2001; Harris et al. 2019). Snorting involves sniffing heroin through a straw or rolled bank note (HRC, 2001; Fig.5). Once in the nose, the heroin is absorbed through the nasal membranes into capillaries and then into the bloodstream (Substance Misuse Resources, 2002). Snorting can have an adverse impact on both the nose and sinuses because the corrosive qualities of some cutting agents can cause nose bleeds (Substance Misuse Resources, 2022). This damage to the nose can facilitate easier transmission of viruses when snorting equipment is shared (Substance Misuse Resources, 2022). Contrary to popular belief, it is still possible to overdose through snorting, although the risk is lower than for injecting. The risk of catching blood borne viruses is also lower for snorting than for injecting, although it is still possible if snorting equipment (e.g. straws) is shared (HRC, 2001).

*Fig.5 Snorting heroin (ARK Behavioral Health, 2020)*



### **2.3.4 Eating**

Raw opium is also eaten in combination with spices, saffron, musk or sugar and swallowed in countries such as India, Pakistan and Burma (UNODOC, 1953). However it is worth mentioning that this UNODOC report was published in 1953, and so this method might be a less contemporary method of use now. Opium is also pounded, mixed with water and consumed as a drink (UNODOC, 1953). Heroin can also be ingested when mixed with water and consumed as a drink and this process is known as ‘eating’ heroin (HRC, 2001). The process of eating heroin is not a popular method of administration because a significant amount of heroin is transformed into morphine during digestion (Carnwath and Smith, 2002). Drugbank (2022) explained that when heroin is administered orally, heroin metabolises rapidly to produce diacetylmorphine and morphine. When heroin, is administered as an injection, acetyl groups in

heroin allows for the rapid passage of diamorphine across the blood-brain barrier (Drugbank, 2022). The crossing of the blood-brain barrier produces rapid onset of activity, compared to the metabolism of oral administration of heroin (Drugbank, 2022).

### ***2.3.5 Stuffing***

Stuffing involves the administration of heroin into the rectum with the use of a syringe barrel (HRC, 2001). Stuffing is relatively safer than injecting because there is less risk of skin/vein damage, scabs, sores and abscesses on skin (San Francisco AIDS Foundation, 2018). This method of administration is associated with damage to the tissue of the rectum and the anus (San Francisco AIDS Foundation, 2018). This damage to the rectum is associated with enhanced risks of transmission of HIV and sexually transmitted infections during the occurrence of sexual intercourse (San Francisco AIDS Foundation, 2018).

### ***2.3.6 Minimising the risks of harm from different routes of administration***

The above discussion highlighted that all routes of administration of heroin are associated with a risk of harm. However certain harm reduction measures can minimise risks to the individual. For example, prior to 2003, users of heroin used lemon juice and vinegar, which often caused eye problems such as the fungal eye infection *Candida endophthalmitis* and blindness (Harris et al. 2019). To reduce the risks associated with the use of lemon juice, Section 9 of the Misuse of Drugs Act 1971 was amended in to permit the provision of citric acid in 2003 and Vitamin C sachets in 2005 (Harris et al. 2019). Other measures to reduce the risk of infection and spread of BBV include the utilisation of clean surfaces for snorting and writing paper instead of rolled bank notes, alternating nostrils and use of clean snorting equipment (HRC, 2001). Administration of water in the nose after the snorting process can help to soothe irritation of the nostrils and exhaling quickly can reduce damage to lungs (HRC, 2001). Harm reduction advice also recommends strongly against sharing of needles but if needles are shared then the syringe must be rinsed with bleach twice followed by cold water (HRC, 2001). Therefore, there are some important ways in which harm can be minimised and these messages need to be shared widely.

Despite these harm reduction measures, there is still a high proportion of people in the UK who share and re-use injecting equipment (PHE, 2020). The Unlinked Anonymous Monitoring Survey (UAMS) strives to assess the incidence of HIV, Hepatitis B and Hepatitis C in people who inject drugs and related risky behaviours (PHE, 2021). According to the most recent results from the UAMS, 20% of respondents from treatment services reported that they shared needles (Welsh Government, 2018). Furthermore, 1 in 4 people who inject drugs have Hepatitis C (PHE et al. 2020). This high incidence of unsafe injecting practices and of Hepatitis C infections highlights the need to improve awareness and find ways of encouraging people to use drugs more safely. Treatment agencies in Wales (and across the world) are an important source of provision of harm reduction advice and play an important role in minimising the risks to individuals who use drugs (Welsh Government, 2019).

#### **2.4 Legal status of heroin**

In addition to the health risks associated with both the effects of heroin and routes of administration, the use of heroin can also have legal repercussions. The current legal position in the UK is that “raw, prescribed or medicinal” opium and heroin are categorised as Class A drugs under the statute (Misuse of Drugs Act 1971). The Misuse of Drugs Act 1971 prohibits unlawful supply, intent to supply, import or export, possession and unlawful production of heroin. The possession of a controlled drug is unlawful, unless there is authorisation for ‘use’ such as a prescription (Release, 2022). Offences involving Class A drugs are associated with more serious penalties in comparison to Class B or Class C drugs. (HM Government, 2021). The maximum sentence for possession of Class A drugs is 7 years imprisonment, an unlimited fine or both. Supply and production of Class A drugs could result in life imprisonment, fine or both (HM Government, 2021).

Prescription of heroin for the treatment of substance dependence is legal in the UK but is subject to strict statutory requirements. This prescription of heroin by a medical practitioner can be distinguished from ‘drug consumption rooms’, which now exist in many countries around the world but not in the UK. In these locations, heroin (and other drug) users are given a safe place to consume illicit drugs (Department of Health (DoH), 2017). However, in the UK the injecting of prescribed heroin (also known as Heroin Assisted Treatment (HAT)) is supervised in appropriate health facilities with the availability of appropriate medical care if

needed (DoH, 2017). Middlesbrough HAT is an example of a Heroin Assisted Treatment programme in the UK (Police and Crime Commissioner for Cleveland, 2020). Middlesbrough HAT is for people have been dependent on heroin for a long time and have not benefitted from traditional OST programmes (Police and Crime Commissioner for Cleveland, 2020). Most doctors prescribe heroin in ampoules that are normally injected but some doses of pharmaceutical heroin are also prescribed in the form of tablets, powders, cigarettes or a solution (Metrebian et al. 2002). Despite legal restrictions on the possession of heroin, a significant number of people use heroin in the UK.

## **2.5 Prevalence of heroin use**

Given the legal status of heroin as a Class A drug, the use of heroin “is a largely hidden or secret activity” (HM Inspectorate of Prisons, 2015, p.17). This secrecy makes it difficult to obtain accurate information about the actual prevalence of the use of heroin (HM Inspectorate of Prisons, 2015). It is therefore unknown how many people use the drug and how frequently they use it (Stevens, 2007). In Criminology terms, this lack of knowledge about the prevalence of heroin use is referred to as the ‘dark figure’ (Stevens, 2007). The following sections will discuss the various methods that have been used to estimate the prevalence of heroin use, with a particular focus on the UK and an emphasis on Wales, where the research presented in this thesis was conducted.

### ***2.5.1 Seizures of illegal drugs***

Seizures of drugs (i.e. the number of seizures and the quantities of drugs seized) made by the police and Border officers are sometimes used to estimate the prevalence of drug use. However, seizures are not always a useful indicator of trends in consumption due to variations in policing activities over time and changes in recording practices that might result in over or underestimates. (Home Office, 2021). The evidence of corruption of officials within drug enforcement agencies suggests seizure figures reflect only the ‘tip of the iceberg’ (Real Reporting Foundation, 2022; National Crime Agency, 2021). This is because they do not account for the quantities of undetected heroin that enters the country or heroin that is allowed into countries because of corruption by officials.

In the year ending March 2020, there were 8,742 seizures of heroin in England and Wales, which is a 4% increase since the previous year (Home Office, 2021). The total quantity of heroin seized by border forces in England and Wales in the year ending March 2020 was 2,394 kg, which is a 217% increase from the previous year (Home Office, 2021). In contrast, over the same period, there was a 31% decline in the quantity of heroin seized by the police in England and Wales (Home Office, 2021). This decline could be indicative of effective avoidance of detection by drug traffickers (Dame Carol Black, 2020). The number of drug seizures peaked in 2009 at 214,473 seizures but the number of drug seizures has been steadily decreasing since then (Home Office, 2021). Recently, there has been a turnaround in this decline and there has been an increase in the number of seizures consecutively, since 2018 (Home Office, 2021). This increase could be attributed to growth in the global supply of drugs as opposed to enhanced enforcement procedures (Dame Carol Black, 2020).

Research suggests that attempts to limit the supply of drugs through seizures does not result in lower rates of drug related deaths or improved treatment outcomes (Dame Carol Black, 2020). Dame Carol Black (2020) argued that even adequate provision of funding to Border and Police forces is insufficient to limit the supply of drugs into the country. This is because illicit drug markets are both highly flexible and resilient to attempts to restrict the supply of drugs into the country (Dame Carol Black, 2020). Furthermore, the enforcement activity associated with drug seizures can actually make the problem worse through a) strengthening violence associated with drug markets, and b) the detrimental impact of involving people arrested for drug offences within the criminal justice system (Dame Carol Black, 2020).

### ***2.5.2 General population surveys***

The Crime Survey for England and Wales (CSEW) is a household survey that is administered to the general population aged between 16-59 years to assess the incidence of crime in the UK. Since 2009, the survey has included questions on the use of illicit drugs. The most recent findings from the CSEW indicate that approximately 3.2 million individuals (or 9.4%) of people aged 16-59 had used drugs in the year ending in March 2020 (Office of National Statistics (ONS), 2020). The CSEW also measures the prevalence of opiate, heroin and illicit methadone use among the general population aged 16-59. In the year ending March 2020, the CSEW found that approximately 22,000 individuals had used opiates in the last year. This included 12,000 who had used heroin and 16,000 who had used illicit methadone. In 2020, for

the first time in the survey's history, the prevalence of drug use was measured among those aged between 60-74. The results showed that drug use was rare among this older population with only 1% reporting illicit drug use in the previous year.

Given that the CSEW is a household survey that excludes important populations that are at an increased risk of illicit drug use (e.g., people who are homeless, people in prison, sex workers and those in residential rehabilitation), its findings could be an under-representation of actual drug use in the UK. For instance, 15% of people in prison reported the use of heroin in the two months prior to imprisonment and 7% of people in prison reported the use of heroin while in prison (HM Inspectorate of Prisons, 2015). Research has also shown that 38% of arrestees tested positive for opiates in police custody suites (Research Development and Statistics Directorate (RDSD), 2004). Similarly, sex workers in Australia reported high levels of heroin consumption (Roxborough et al., 2005). Evidently, use of heroin is far higher among these populations than among the general population.

The stigma of drug use and its illegal status could also mean that individuals completing self-report surveys are less likely to admit to consumption of illicit drugs (Harrison, 1997). There may also be problems with recall particularly when respondents are being asked about their frequency of drug use over a long period of time and when their memory may be impaired by intoxication (Johnson, 2014). Despite these weaknesses, the findings of the CSEW are beneficial as they provide an approximation of the prevalence of drug (including opiates, heroin and illicit methadone) use within the general population in the UK.

### ***2.5.3 Police-recorded crime data and court data***

Police recorded crime provides information on the perpetration of drug-related offences including possession which could be a proxy for use (ONS, 2018). Police recorded crime data is based on data available at the time that the offence is noticed by the police (ONS, 2018). Between 2019-2020, there were 69,000 arrests for drug offences in England and Wales (House of Commons Library (HCL), 2021). Most arrests are for possession of drugs (HCL, 2021). This has fallen from a peak of 119,000 arrests for drug offences in 2010/2011 (HCL, 2021). However, the frequency of arrests describes the policing activity, as opposed to an actual reflection of the crime activity (HCL, 2021). Police records show that the lockdown restrictions in response to the COVID-19 pandemic were related with an increase in perpetration of drug

offences, particularly for possession of drugs in England and Wales (ONS, 2020). In April 2020, there was a 22% rise in the commission of drug offences, when compared with April 2019 (ONS, 2020). This increase in drug offences has been attributed to increased police activity and more ‘stop and searches’ (ONS, 2020). The increase could also be attributed to increased likelihood of detection because of less crowded areas during the lockdown period.

Looking at Welsh data specifically, between 2019-2020, the rate of recorded drug offences by police was 3.1 per 1000 individuals (ONS, 2020). In South Wales, in the year ending September 2021, police recorded crime statistics showed that there were 4,966 drug offences (ONS, 2022). However, police recorded data must be considered in the context that the accuracy is affected by inconsistency of reporting across police forces, changes in recording practices and alterations in patterns of reporting crime rates by the public (ONS, 2018). Furthermore, police recorded crimes are not always broken down on the type of drug involved, so they are not that useful in measuring heroin or opioid-related crimes specifically.

#### ***2.5.4 Health-related data***

Health-related data can also be used to gauge the extent of heroin use in the UK. However, health-related data provides a better measure of problematic use than general or recreational use. The most serious health problem associated with heroin use is death. Opioids accounted for the greatest proportion of drug poisoning deaths in England and Wales in 2020 (2,263), which is 48% more than in 2010 (Office for National Statistics (ONS), 2021). In 2017, heroin/morphine deaths accounted for nearly half (45%) of all drug misuse deaths in Wales (PHW, 2021). Out of the heroin/morphine deaths, roughly half (49%) of the death certificates recorded the use of another substance in addition to heroin in Wales (PHW, 2021). The number of heroin related deaths has decreased from 108 in 2018 to 73 in 2019 (PHW, 2021). The stabilisation of the number of overdose deaths in Wales (unlike in England and Scotland) has been attributed to enhanced accessibility to naloxone, which is a drug that is used to reverse an opioid overdose (Mahase, 2022).

Hospital data is another source of data that can be used to estimate the number of people who are experiencing difficulties with opioid use (Friebel and Maynou, 2022). Friebel and Maynou (2022) analysed data from the Hospital Admissions Database from 2008 to 2018 in England.

The number of opioid associated hospitalisations was found to rise by nearly half (49%) from 10,805 admissions in 2008 to 16,091 admissions in 2018 (Friebel and Maynou, 2022).

In Wales, opioid use is also associated with a greater number of hospital admissions than any other substance group (Public Health Wales (PHW), 2021). Between 2019-2020, there were 2,736 opioid-related hospital admissions in Wales (PHW, 2021). This is a decrease of 13% compared with the previous year (PHW, 2021). Mahase (2022) attributed the stabilisation of overdose deaths to increased accessibility of naloxone. Therefore, the decline in opioid-related admissions could be partially attributed to widespread accessibility of naloxone in Wales. The European Age Standardised Rate for opioid-related admissions was 92.7 per 100,000 in 2019-2020, which is a 14.4% rise since 2012-2013. Friebel and Maynou (2021) state that the significant rise in opioid-related hospital admissions underlines that the impact of opioid use is not confined to mortality but extends to other health harms. Furthermore, the increase in opioid-related hospital admissions places pressure on the National Health Service (Friebel and Maynou, 2021).

Treatment entry statistics are another important way in which the prevalence of problematic heroin use can be measured. In 2018, 114,752 individuals commenced treatment for substance misuse problems in England and Wales half of whom stated that their primary drug was opioids (Focal Point, 2021). Of 275, 896 individuals who were in continuous treatment in England and Wales, (i.e., those who were in treatment at the beginning of the calendar year when data were collected), nearly three-quarters (71%) stated that heroin was their primary substance (Focal Point, 2021).

### ***2.5.5 Capture-recapture method***

PHW (2021) define problematic drug use as “injecting drug use or long duration/ regular use of opioids, cocaine and/or amphetamines” (p.91). According to this definition, there are 52,980 individuals who use drugs problematically in Wales. This figure was obtained through the capture-recapture method, which involves “modelling interactions between datasets containing the substance misuse population that is ‘visible’ to health, treatment or criminal justice services to generate statistical estimates for the ‘hidden’ population who are not in contact with any service” (PHW, 2021, p.91).

### **2.5.6 Summary**

There are two main conclusions to draw from this review of data sources. First, despite the illegal nature of heroin and significant negative legal consequences related to its possession and/or supply and the risks associated with different routes of administration, it is clear that a significant proportion of people use heroin in the UK. Second, it must be noted that the actual number of people who use opioids is likely to be far higher than the data suggest because of methodological issues such as sampling and problems with accurate recall. One particularly important methodological issue relates to the illegal status of heroin and the fear of legal sanctions if illegal behaviour is disclosed. These two points raise the important question of the reasons why people use heroin despite the potential health harms and legal repercussions.

### **2.6 Definition of addiction and dependency**

Drugs research has differentiated between the terms ‘addiction’ and ‘dependency’, (Maddux and Desmon, 2000). Addiction is defined as the inability to stop the consumption of the drug (NIDA, 2018). Addiction also means that the person is unable to meet work, social and family commitments (NIDA, 2018). Wise and Koob (2014) state that prolonged use of drugs creates memories of drug experiences and changes to the brain. Both these factors lead to compulsion and strong cravings, which in turn are the initial indicators of addiction (Wise and Koob, 2014). The definition of addiction is complex because the onset of addiction does not happen at a defined point but is a gradual progression from the first use to addiction (Wise and Koob, 2014). Psychological dependence can be described as the use of drugs on a continual basis to generate pleasure or alleviate pain (The Effective Security Officer’s Training Manual, 2014).

Addiction can also be accompanied by physical dependency for certain types of drugs (NIDA, 2018). Physical dependency describes the body’s adaptation to the drug i.e., the body needs more and more drug to achieve the same effect (tolerance) or the onset of physical or mental symptoms (withdrawal) upon stopping the use of drug (NIDA, 2018). However, this onset of withdrawal does not always mean that someone is addicted (NIDA, 2017). For instance, Wise and Koob (2013) argue that onset of withdrawal is not in itself a reliable indicator of addiction, because it fails to account for the pre-existing habit that led to the onset of withdrawal.

The Scottish Drug Forum (SDF, 2020) stated that the term ‘addiction’ should be avoided. This is because the term ‘addiction’ is “described as a chronic, relapsing disease characterised by compulsive drug seeking and use despite adverse consequences and long-lasting changes in the brain” (SDF, 2020, p.9). SDF (2020) argued that the disease and medical connotations with the term ‘addiction’ means that the influence of factors such as adverse childhood experiences, poverty and social situation are neglected in the definition of problematic use of drugs. SDF (2020, p.8) also stated that the word ‘addict’ can be used in ways that are “dehumanizing, disempowering and stigmatising”. In my previous experience as active treatment worker, the words ‘addiction’ and ‘addict’ were also perceived to be associated with stigma. For these reasons, I will avoid the use of the word ‘addiction’ and use the word ‘dependency’ hereon, as recommended by SDF (2020).

### ***2.6.1 Compulsion v choice***

Wise and Koob (2014) argued that prolonged use of drugs creates memories of drug experiences and changes to the brain. Both these factors lead to compulsion and strong cravings, which in turn are the initial indicators of addiction (Wise and Koob, 2014). Carnwath and Smith (2002) however argue that despite the immense discomfort of these withdrawal symptoms, humans still have the choice to bear the pain that they cause. In other words, the presence of withdrawal symptoms does not mean there is a chemical compulsion to use drugs (Carnwath and Smith, 2002). The existence of positive social networks and structured activities are powerful enough to overcome the chemical dependency or withdrawal symptoms of heroin use (Carnwath and Smith, 2002).

Heather (1998) also argues that compulsion connotations have dangerous implications for treatment services, because it presumes that individuals cannot stop the use of drugs and prevents change in behaviour. At this point, it is important not to minimise the extreme pain and discomfort of withdrawal symptoms. During my experience as an active treatment worker within drug services, many OST patients described the immense pain of withdrawal. However, from a theoretical perspective, an important point is that persistence and the onset of withdrawal symptoms upon cessation of heroin use does not automatically equate to use of heroin in an uncontrolled, dependent manner. A favourable definition of dependency should

acknowledge the difficulty of alterations in drug using behaviour and should avoid the presumption that there is no choice (Heather, 1998). This suggests that the ‘loss of control’ within the definition of addiction, is not based on an inevitable compulsion, but the difficulty in stopping the use of drugs. The debate between choice and compulsion and the difficulty in the determination of the exact point of dependency, highlights the difficulty in describing the term. Having established what dependence means, it is important to now reflect on the factors that lead people to become dependent on heroin. Zinberg’s (1984) *drug, set and setting* framework provides a useful structure for examining the various factors involved.

## **2.7 Zinberg’s (1984) *drug set and setting* framework**

Zinberg and Harding (1984) stated that *drug, set and setting* variables influence the consumption of drugs. Furthermore, the *drug, set and setting* factors interact in complex ways to determine who use drugs, the routes of administration and the effects of the drug (Zinberg, 1984). While the framework was originally developed to explain drug use, the approach has been used to explore the “complexities and dynamics of the wide range of patterns of drug using behavior” (Shewan, 1999, p.7), including overdoses and the efficacy of interventions targeted at sniffing petrol (Atiantis et al. 2020; Lamonica, Boeri and Turner, 2021; Richert, 2015; Lau et al. 2015; MaClean and D’Abbs, 2002).

### **2.7.1 Drug**

*Drug* variables can be described as the pharmacological effects of the drug and “pharmacological aspects of the experience” of using the drug (Zinberg 1984 as cited in Lau et al. 2015, p.2). Frequency of drug use, method of administration, potency of the drug, quantity of the drug, mixing with cutting agents and varying degrees of purity are categorised as *drug* variables because they are associated with the pharmacological effects of the drug (Zinberg, 1984; Ataiants et al. 2020; Shewan et al. 2000). The methods of obtaining the drug, different forms of the drug and effects of polysubstance use have also been described as *drug* (Shewan et al. 2000; Lau et al. 2015; Lamonica et al. 2021).

However, the effects of drugs vary from person to person (Wright, 2013). The pharmacological experience of the drug may be influenced by personality attributes, expectations, and information from the media (Otter and Martin, 1996 as cited in Wright, 2013; Gossop, 2013;

Zinberg, 1984). The emphasis on the pharmacological effects of drugs within the literature has resulted in a tendency to overlook the importance of psychological (or *set*) and social (*setting*) factors in explaining patterns of drug use (Shewan, 1999; Zinberg, 1984).

### **2.7.2 Set**

*Set* was originally defined as “the attitude of the person at the time of use” (Zinberg, 1984, p.5). However, since then it has been used more broadly to include a wide range of other mind-*set* related factors including current psychological states as well as more fixed personality traits. Within the literature, previous negative life experiences, long-lasting emotional trauma and current emotional states of mind have all been described as *set* (Lamonica et al. 2021, p.7). Furthermore, personal characteristics and personality attributes have been categorised as *set* factors along with previous experiences of drugs, mood, motives and expectations of the person who uses drugs (Jansen,1997; Lau et al., 2015, Mui et al., 2014).

Dalgarno and Shewan (2005) stated that “being knowledgeable, thoughtful and well-prepared for using drugs, pretty well any drug, minimizes the risks and dangerousness of the experience, and maximizes positive aspects of the experience” (Dalgarno and Shewan, 2005, p.264). *Set* factors are powerfully connected to the experience of the drug. *Set* and *drug* factors are therefore closely connected and often interact.

### **2.7.3 Setting**

Setting can be described as “the influence of the physical and social setting within which the use occurs” (Zinberg, 1984, p.5). Physical setting is described as “the place, people and things *present* during the time of use” (Mui et al. 2014, p.238; Lamonica et al. 2021). The change in physical setting such as leaving treatment or prison release has also been described as *setting* (Lamonica et al. 2021). In terms of the social setting, this has been described as the group of other people present when use occurs (i.e., their broader values and beliefs) and social relationships with others (Mui et al. 2014). The social setting is important in that it can control the consumption of drugs through sanctions and rituals (Zinberg, 1984). Formal or informal social sanctions can determine if and how a drug should be used. “Social rituals are the stylized, prescribed behavior patterns surrounding the use of a drug” (Zinberg, 1984, p.5). Examples of social rituals include ways of obtaining and using the drug, the choice of the appropriate

physical/social setting, engagement in activities after the drug use and techniques used to prevent undesirable effects of drug use (Zinberg, 1984).

The *drug, set and setting* “variables interact in complex ways to influence who uses an intoxicant, how it is used and what its effects are” (Zinberg and Harding, 1979; p.124). The acceptance of complex interactions between the *drug, set and setting* factors is commendable because it reflects the complexity of human behaviour. However, these complex interactions can in themselves become a limitation because the boundaries can sometimes become blurred (Lamonica et al. 2021). Furthermore, the classification of *drug, set and setting* factors may be susceptible to subjective interpretations. However, these limitations can be overcome by drawing on past research and developing a clear rationale for classifying factors in a particular way. The next section will discuss *drug, set and setting* factors within Zinberg’s (1984) framework that could explain why some people become dependent on heroin.

## **2.8 Drug factors**

The concept of dependency has been primarily understood through studying a) treatment populations who continue to use heroin while engaged with treatment for heroin dependency, b) individuals who continue to use heroin on a controlled or occasional basis, and c) heroin dependent individuals who are not engaged with treatment services for a variety of reasons such as homelessness. This section will present *drug* factors that could explain why some people become dependent on heroin. As discussed above, *drug* variables can be described as the pharmacological effects of the drug and “pharmacological aspects of the experience” (Zinberg, 1984; Zinberg 1984 as cited in Lau et al. 2015, p.2).

### **2.8.1 Alleviation of pain and stress**

The drug specificity postulate of the self-medication hypothesis (SMH) suggested that the choice to use a particular drug is based on the ability of its psychopharmacological effects, to alleviate distressing symptoms of trauma or psychopathology (Darke, 2013). For instance, “opioids are argued to attenuate intense, rageful and violent affect” (Darke, 2013, p.660). However, many people who use heroin also use a number of other drugs too (Darke, 2013). This poly-drug use suggested that people who use heroin seek the ‘intoxication’ to numb the pain, as opposed to the specific pharmacological effects of heroin (Darke, 2013). Darke (2013)

stated that polydrug use is related with increased risk of overdose, suicide, psychopathology and poorer treatment outcomes. All these factors could increase the likelihood of individuals being locked within ‘dependency’.

Tsuang et al. (1999) interviewed male-twin pairs to explore the genetic and environmental influences in transition to abuse of drugs. Tsuang et al. (1999) stated that the transition to regular use of heroin is influenced by factors such as variations in the experience of the subjective effects of heroin, amount of stress and capacity to cope with stress in a non-drug related manner (Tsuang et al. 1999). Furthermore, these three variations could in turn be affected by genetic and environmental factors (Tsuang et al. 1999). This suggested that the transition to dependency is influenced by a complex myriad of factors such as individualised experiences of effects of drugs and environmental factors.

### ***2.8.2 Pleasure***

The use of heroin is related with a “warm cocooning comfort ...that can be very seductive” (Picardie and Wade, 1985, p.6). According to the social learning theory, the experience of pleasurable effects of the drug will strengthen motivation to use heroin on a persistent basis (West and Brown, 2013). Warburton et al. (2002) qualitative study showed that non-dependent or controlled users of heroin experienced pleasure from heroin. However, one finding was that these non-dependent and controlled users of heroin remained in control of behavioural actions and the heroin use was one of many sources of relaxation and pleasure (Warburton et al. 2002). Wise and Koob (2014) state that the early stages of dependency are characterised by positive reinforcements such as pleasure, while the latter stages are characterised by negative reinforcements such as avoidance of withdrawal. However, Valentine and Fraser’s (2008) qualitative study found that the effects of heroin were still pleasurable for individuals who were in treatment for their dependent use of heroin. This finding challenged the strength of the SMH, as it showed that individuals with traumatic experiences use heroin for pleasurable reasons too (Valentine and Fraser, 2008).

Yet, treatment services often presume the use of heroin within OST is only problematic and not pleasurable, because people who use drugs recreationally do not access treatment services (Valentine and Fraser, 2008). Treatment services are aware of the pleasures of heroin but “pleasure is often suppressed or submerged in policy and practice” (Valentine and Fraser, 2008,

p.414). One implication of this ‘suppression’ of pleasure by treatment services is that it prevents OST patients from articulating the reasons that they use drugs (Valentine and Fraser, 2008). The neglect of pleasure could also reduce the efficacy of harm reduction interventions because they could be perceived as negative (i.e., they will reduce the pleasure) or irrelevant (Holt and Treloar, 2008).

Research has also shown that the environment can influence the effects of a drug. For example, people have been found to persist in heroin use in prison because it helps to alleviate boredom and promote relaxation (Strang et al. 2006). Neale’s (2001) qualitative study of homeless drug users in Scotland also showed that heroin was a coping mechanism for homelessness and helped to numb both emotional and physical pain. Many homeless participants expressed a desire to stop their use of heroin but most drug services are unable to meet the needs of homeless participants (Rowe, 2005). For instance, many homeless individuals are unable to attend appointments because of pressing immediate needs, particularly when the homeless participant is exposed to drug-using peers (Rowe, 2005).

### ***2.8.3 Effects of heroin on the brain***

Other theories have suggested that the impact of heroin on the brain could contribute to dependency. The use of heroin raises the concentration of the neurotransmitter dopamine in the nucleus accumbens part of the brain (West and Brown, 2013). Heroin stops the inhibitory control of gamma-aminobutyric acid on the ventral tegmental area of the mid brain, which results in more firing of neurones leading to the nucleus accumbens of the brain (West and Brown, 2013). This increased concentration of dopamine levels facilitates the occurrence of dependency, because it influences the rewarding effects of cues (West and Brown, 2013). Robinson and Berridge’s (2001) incentive sensitization theory also postulated that persistent use of heroin resulted in changes to the brain. These neuroadaptations enhance the sensitivity of reward systems to drug cues and generate intense cravings or ‘wanting’ for the drug in the absence of withdrawal or pleasurable effects of the drug (Robinson and Berridge, 2001). This theory has helped to partially explain why some people persist in the use of heroin despite the negative consequences associated with dependency.

#### **2.8.4 Tolerance and withdrawal**

Tolerance and withdrawal are classed as *drug*-related factors because they are associated with increased consumption of heroin (Zinberg, 1984). Frequent and increased consumption of heroin transforms the brain (Kosten and George, 2001). These changes in the brain mean heroin consumption is needed for normal functioning of the brain (Kosten and George, 2001). The impacts of this transformation are an increased tolerance and development of withdrawal symptoms when use is stopped or reduced (Kosten and George, 2001). This means that more and more heroin will be needed to achieve the positive effects of heroin and eventually just to function through the day. As tolerance develops, when use stops or reduces, the user may experience unpleasant withdrawal symptoms such as “nausea, vomiting and abdominal cramps” and “restlessness, insomnia, muscle spasms and low back pain” (Hodding, Jann and Ackerman, 1980, p.387-388).

This intense pain of withdrawal symptoms has been noted to be a strong factor in driving the persistent use of heroin and deemed to be indicative of dependency (Wise and Koob, 2014; Warburton et al. 2005). Furthermore, the pain of withdrawal is intensified for the homeless population because they have to cope with both extreme weather and painful withdrawal symptoms (Neale, 2001). This combination of withdrawal symptoms and adverse weather could increase the likelihood of continuation and escalation of heroin use in the homeless population. However, Warburton et al. (2005) state that it is possible to use heroin in a controlled and non-dependent manner even if an individual experiences withdrawal symptoms upon cessation of use, provided the use of heroin is largely free of problems with housing and employment. As discussed earlier in this chapter, the presence of withdrawal symptoms in itself is not a definitive indicator of dependency or uncontrolled use of heroin.

#### **2.8.5 Route of administration**

The point at which someone starts to inject can be described as as a *drug*-related factor (Zinberg, 1984). Research has shown that people who injected at the initiation stage were more likely to use heroin daily within a month of initiation (Hines et al. 2017). Injection produces increased concentration of drug in blood stream and has increased bioavailability in comparison to smoking (Hines et al. 2017). Injection at initiation has been associated with the development of drug dependence because of “the increased efficiency of drug delivery” (Hines et al. 2017, p.636). It can therefore be assumed that a similar mechanism can explain the rapid

transition from injecting to daily use of heroin (Hines et al. 2017). The rapid alteration from normal levels to intense pleasure could motivate repeated drug consumption (NIDA, 2007).

Data from the Harm Reduction Database in Wales, shows that the self-reported rate of injecting opioids at the groin has remained fairly stable in the range of 20%-21% from 2016-to 2021 in Wales (PHW, 2021). Persistent use of drugs could lead to vascular damage in arms (PHE, 2018). This means that persistent users of heroin may switch to injecting in the groin, because no other injecting sites are available (PHE, 2018). Injecting in the groin may result in damage to the femoral artery, vein and nerve, which in turn could exacerbate physical health issues (PHE, 2018).

Needle fixation is described as “repetitive puncturing of the skin with or without the injection of psychoactive drugs via intravenous, subcutaneous or intramuscular routes, irrespective of the drug or drugs injected or the anticipated effects of the drug” (Pates et al. 2001; p.15). This needle fixation can be described as *drug* because it describes an attachment to the method of use that is not necessarily dependent on the anticipated effects of drugs (Zinberg, 1984). In heroin users, the continued injection of drugs means that needle fixation becomes a conditioned response. This means that users get a secondary stimulation too. The secondary stimulus is activated by the preparation of injection and injection itself (Pates et al. 2001). This stimulation leads to persistence of drug use. Furthermore, individuals with needle fixation are more likely to have obsessive characteristics which in turn further strengthen the ‘needle fixation’ phenomenon (Woolridge, 2017). This suggests that some individuals are more vulnerable to the influence of needle fixation.

McBride et al. (2001) interviewed heroin users from drug agencies in South Wales to explore their perspectives of needle fixation. McBride et al. (2001) found that injecting was associated with rewards such as sexual pleasure, release of self-harm, masochistic experience of pain and social status. This connection between responses and injecting was termed as ‘chaining’ (McBride et al. 2001). Furthermore, in my experience as a drug worker, many heroin dependent patients stated that they experienced pleasure in the ritual preparation of heroin and the physical act of injecting as opposed to the actual effects of heroin. This needle fixation may mean that optimal prescribing treatment is insufficient to stop injecting behaviour if the conditioning and ‘chaining’ are not addressed (Pates et al. 2001; McBride et al. 2001).

To summarise, the *drug* factors of alleviation of pain and stress and pleasurable effects of heroin use could contribute to persistent use of the drug. The effects of heroin on the brain, tolerance, withdrawal, route of administration are also *drug* factors that contribute to continued use of heroin.

## **2.9 Set factors**

*Set* is defined as “the attitude of the person at the time of use” (Zinberg, 1984, p.5). To recap, *set* factors include personality, emotional states of mind, expectations of the persons and previous negative life experiences (Jansen,1997; Lau et al., 2015, Mui et al., 2014; Lamonica et al. 2021). This section will explore how *set* factors could explain why some individuals become dependent on heroin.

### ***2.9.1 Distorted cognitions and denial***

One question that has baffled many people is the reason why individuals continue to persist in the use of heroin despite the experience of negative consequences. Pickard (2016) partially answered the question by stating that individuals who use heroin have distorted cognitions such as denial which block the knowledge that the use of heroin can cause negative consequences. Howard et al. (2002) conducted focus groups with individuals at chemical dependency treatment facilities to explore the role of denial in the development of dependency. Drug-related stigma, the fear of facing the difficult task of achievement of recovery after a prolonged period of drug use and belief that their own behaviour did not match the stereotypical views of the drug dependent person were deemed to contribute to denial (Howard et al. 2002). The lack of awareness of seriousness of use, especially if peers were using the same level of substances contributed to denial of dependency (Howard et al. 2002). The use of confrontation by treatment agencies in response to denial led to frustration in individuals dependent on drugs (Howard et al. 2002). Pickard (2002) recommended that treatment agencies should acknowledge and treat the cognitive distortion of denial.

### **2.9.2 Personality and personality attributes**

Research is divided on whether personality disorders is the result of dependency on drugs or if pre-existing personality disorders leads to dependency on drugs (Gomez, Garcia and Collado, 2008). To truly determine if certain personality disorders are associated with increased likelihood of dependency, researchers must conduct prospective studies at the early stages of dependency (Gomez et al. 2008). Early research studies that compared the scores of dependent individuals with non-dependent individuals on personality tests have not found a significant difference in personality scores (Platt, 1975; Gendreau and Gendreau, 1970). Platt (1975) concluded that dependency cannot be explained by the ‘addictive personality’. Recent research has focussed on the influence of drug consumption on neurobiological areas, which in turn has an impact on personality attributes such as impulsivity (Gomez et al. 2008).

Personality attributes have been categorised as *set* (Mui et al. 2014). Long term use of heroin is also related with decreased gray matter in the frontal and limbic areas in the brain and with modifications to cortical thickness in the brain (Li et al. 2014). This decreased cortical thickness has been linked to impulsive consumption of drugs (Li et al. 2014). This connection between changes in physiology and impulsivity could result in increased consumption of heroin and loss of control. This loss of control has been deemed to be a key characteristic of dependency (NIDA, 2017).

Defence styles can be described as protective psychological mechanisms that buffer the individual against anxiety and stressors (DSM-IV, American Psychiatric Association on Nomenclature and Statistics, 1994, as cited in Evren et al. 2012). The defence style is also considered to be an important component of the structure of personality (Evren et al. 2012). Evren et al. (2012) compared the defence styles of heroin dependent patients with a control group, through administration of the Defense Style Questionnaire. The heroin dependent population were characterised by more immature defence styles, especially acting out and splitting (the holding of conflicting attitudes towards other people and self because of contradictory emotions) in comparison to the control group (Evren et al. 2012; Boag, 2017). The use of immature defences stops the conscious awareness of disturbing stimuli (Evren et al. 2012). Evren et al. (2012) therefore concluded that those with immature defences will use substances as a way of avoiding problems. Furthermore, the immature defences were found to

be associated with history of emotional abuse (*set*) in the population of heroin dependent patients (Evren et al. 2012). Therefore, the presence of other *set* factors such as trauma could increase the likelihood of development of immature defences, which in turn could strengthen the probability of the onset of dependency.

### **2.9.3 Mood**

Witteveen et al. (2007), found that 90% of interviewees who went on to use heroin problematically had been experiencing problems such as divorce, involvement with foster care/juvenile correction institutions, sexual violence, family arguments and death of parents at the time of initiation. Similarly, Liao et al's (2011) study which involved the administration of self-reported questionnaires to heroin dependent patients, showed that they experienced more negative life events than positive life events. This incidence of negative events was related with anxiety and depression (Liao et al. 2011). The high number of stressful events at the time of initiation and the increased incidence of negative life events/negative mood states suggested that heroin dependent individuals could use heroin to alleviate negative moods (Witteveen et al. 2007; Liao et al. 2011).

Hogarth et al. (2019) explored the impact of negative mood on the desire to use heroin through the comparison of heroin dependent patients and control group. Heroin users filled in a questionnaire to explore the reasons for use of heroin: negative mood, social pressure, and craving. Negative mood was stimulated through the use of depressive statements and sad music. The choice to use heroin was assessed by the desire to enlarge heroin pictures as opposed to pictures of food. Subjective reactivity was noted by recording positive and negative mood levels pre and posttest. The mood stimulated heroin choice was related with self-reported use of heroin to cope with negative mood, but not social pressure or craving. Hogarth et al. (2019) concluded that the use of heroin to alleviate negative moods, increases sensitivity to negative affect triggers and enhances the likelihood of development of heroin dependence.

### **2.9.4 Previous traumatic experiences and psychopathology**

Darke (2013) argued that the existence of psychopathology and childhood trauma prior to the onset of heroin use, is evidence that heroin is used as self-medication to alleviate the distressing effects of trauma and psychopathology. This theory is called the self-medication hypothesis

(SMH). I will now explore in turn how both the *set* factors of psychopathology and previous traumatic experiences could contribute to the development of heroin dependence.

Darke and Ross's (1997) Composite International Diagnostic Interviews with heroin injectors (engaged with OST, therapeutic community or not engaged with treatment) showed that there was an increased incidence of depression and anxiety within this population. According to the University of Manchester's (2016) report, 38% of people who had died of suicide in Wales between 2004-2014 had a history of heroin misuse. These findings strongly suggest that continual use of heroin could be motivated by a desire to alleviate the distressing symptoms of psychopathology. Darke (2013) therefore argued that self-medication plays a strong role in the development of heroin dependency.

The high incidence of psychopathology among people who use heroin provides some evidence for the SMH. However, West and Brown (2013) argue that SMH does a) not account for the immense psychological distress associated with excessive use of drugs, and b) does not explain why individuals with no psychopathology become dependent on heroin. DuPont and Gold (2007) also reasoned that the SMH could have detrimental implications for treatment services. For instance, belief in the SMH could result in the treatment of psychopathology at the expense of neglecting the treatment of drug use as a separate disorder (DuPont and Gold, 2007).

The population of opioid dependent individuals have a disproportionately increased incidence of childhood trauma (Carlyle et al. 2021). This high incidence of previous traumatic experiences within the opioid dependent population is indicative that heroin is used to soothe the effects of trauma (Darke, 2013). However, Breslau (2013) argued was that only those who develop post-traumatic stress disorder as a result of traumatic experiences, are at increased risk of the development of heroin dependence. Individuals who have PTSD because of trauma are more likely to use heroin to self-medicate the symptoms of PTSD (Breslau, 2013). Furthermore, Breslau (2013) stated that individuals with drug disorders and related psychiatric disturbances could be more biased to the recall of negative experiences, in comparison to those with no psychiatric disturbances. This bias in turn could result in the 'so called' association between the history of trauma and development of dependence (Breslau, 2013). The relation between trauma and the onset of dependence also fails to consider the influence of genetic factors that maybe encompassed with child abuse (Breslau, 2013). Lembke (2013) argued that trauma is a risk factor for the development of dependency but does *not* cause dependency.

Furthermore, Lembke (2013, p.670) stated that “A(a)ddiction results from the complex interplay between risk factors, the reinforcing properties of the substances themselves and the learned behavior and rituals associated with habitual use.” Lembke (2013) therefore emphasised the role of cultural and environment factors in the development of dependency, as opposed to the specific characteristics and background of the individual.

To summarise, the *set* factors of distorted cognitions, personality, mood, previous traumatic experiences and psychopathology could explain why some people become dependent on heroin. The next section will explore how *setting* factors could contribute to the onset of heroin dependency.

## **2.10 Setting factors**

*Setting* can be described as “the influence of the physical and social setting within which the use occurs” (Zinberg, 1984, p.5). The changes in social setting, social relationships, social sanctions and social rituals have also been described as *setting* (Lamonica et al. 2021; Mui et al. 2014; Zinberg, 1984).

### **2.10.1 Drug using social network**

People with uncontrolled drug use are often found to break ties with non-drug using networks and form friendships with drug-using peers (NIDA, 2004; Hser 2007). However, controlled users of heroin have been found to avoid people entrenched within the drug-using culture or criminal activity and socialise with people who also control their use through boundaries (Warburton et al. 2005). Fergusson, Boden and Horwood’s (2008) 25-year longitudinal study of New Zealand children showed that people associating with drug-using peers were five times more likely to develop drug dependence, in comparison with those who did not have drug-using peers. This relation could be because peers a) give information to drug using peers, b) supply drugs and c) provide social support which facilitates the use of drugs (Fergusson et al. 2008). Drug-using peers have been found to contribute to the development and acceptance of favourable definitions of heroin consumption (Jacquith, 1981). This increased incidence of favorable definitions of substance use will mean that the individual will feel that the use of substances is related with rewards and benefits and will be more likely to use drugs (Ward and Brown, 2015).

### **2.10.2 Living environment**

The high incidence of heroin consumption in disadvantaged areas has also been linked to the development of favourable definitions of heroin use (Cressey, 1960). As heroin use becomes more common in disadvantaged areas, there is less exposure to learning concepts associated with abstinence from heroin (Cressey, 1960). Therefore, heroin users from socially disadvantaged areas may have deeply entrenched favourable definitions of heroin use. The experience of social disadvantage or social exclusion may have important implications for treatment services. For instance, the continuing presence of social exclusion (*setting*) may mean that abstinence and freedom from physical/psychological dependency (*drug*) will not always lead to productive and meaningful changes in the heroin dependent individual's life (Buchanan, 2004).

The definition of dependency is complex given that it is difficult to pinpoint the exact point of the onset of dependency. As explained earlier, persistence in the use of heroin and the onset of withdrawal in itself does not equate to dependency. This suggests that there is a group of individuals who are fortunate enough to use heroin and not become dependent on the drug. However, research has shown that certain *drug, set and setting* factors can increase the likelihood of the development of dependency. This raises the important question how individuals try to overcome their dependency on drugs?

### **2.11 Recovery**

While some people are able to stop using heroin naturally without recourse to professional support and treatment, many are not so fortunate. It is important to understand the antecedents of recovery, as they could inform the development of interventions that could help others who are struggling to overcome their dependency. The next section will therefore discuss a) how some dependent individuals are able to stop the use of heroin naturally without the need of formal support (natural recovery) and b) existing interventions that aim to support individuals who are struggling to overcome their dependency on heroin (assisted recovery).

### ***2.11.1 Natural recovery***

Natural recovery can be described as “natural in the sense that some addicts manage to stop using heroin and not become re-addicted without the help of treatment intervention” (Waldorf and Biernacki, 1979, p.281). Research has identified that a significant proportion of dependent individuals overcome dependency without the aid of formal treatment (Granfield and Cloud, 1996). However, it is difficult to ascertain the exact number because of the ‘invisibility’ of this population (Granfield and Cloud, 1996). Waldorf and Biernacki’s (1981) qualitative interviews with untreated heroin individuals showed that tiredness of drug using lifestyle (*set*) and simultaneous occurrence of important personal experiences (*setting*) such as witnessing a loved one die of overdose contributed to cessation of heroin use. Untreated individuals also took proactive steps to move away from the drug using network (*setting*) and formed a new social identity (*set*). Waldorf and Biernacki (1981) stated that heroin using individuals who are able to maintain non-drug using identities during periods of use have a stronger likelihood of overcoming dependence without the need for support from treatment services. One important implication of these findings is that treatment services should focus on the development of new social identities through encouraging clients to search for employment, develop productive relationships and undertake new personal responsibilities (Waldorf and Biernacki, 1981).

The added advantage of the development of new relationships and engagement in employment is the provision of incentives to stop the use of heroin (Granfield and Cloud, 1996). Granfield and Cloud (1996) interviewed individuals who had a history of dependency (experience of cravings, prolonged periods of use and problems related to drug use) with limited or no experience of treatment. Participants used resources such as family relationships, employment and emotional security to overcome dependency from heroin (Granfield and Cloud, 1996). An important implication is that heroin dependent individuals from disadvantaged backgrounds (*setting*) may not have the necessary resources to achieve natural recovery (Granfield and Cloud, 1996). Best (2019) argued that community support is needed in addition to formal treatment to empower heroin dependent individuals from disadvantaged backgrounds to achieve recovery. This support from the community could be invaluable in increasing the resources of heroin dependent individuals from disadvantaged backgrounds. Participants also placed immense importance on their current social identity as opposed to fixation on exploration of their previous “drug using identity” (Granfield and Cloud, 1999). This suggests

that treatment services should consider adopting an approach that is focussed on the present to achieve benefits from treatment.

The discussion on ‘natural recovery’ identifies that comprehension of the factors that contribute to ‘natural recovery’ could inform the development of appropriate treatment interventions, which could in turn improve the wellbeing of patients engaged with treatment services. Despite the existence of ‘natural recovery,’ research has suggested that some people may struggle with natural recovery because of an absence of non-drug using identities or lack of resources because of disadvantaged backgrounds. This group may need the assistance of formal treatment services to overcome heroin dependency.

### ***2.11.2 Assisted recovery (i.e., treatment)***

This chapter has referred to populations in treatment for heroin dependency when describing persistence of heroin use. In the UK, opioid substitute treatment (OST) is an important intervention that is used to treat dependency on heroin or illicit opioid dependency (Public Health England (PHE), 2021). OST comprises both of pharmacological and psychosocial elements (PHE, 2021). The pharmacological element involves the substitution of the use of illicit opioids with prescribed opioids such as methadone or buprenorphine (PHE, 2021). These medications diminish or stop withdrawal symptoms and also alleviate cravings, without the generation of highs associated with heroin (PHE, 2021). At the optimal dose, substitute medication can block the ‘high’ of heroin (PHE, 2021). The psychosocial element or talking helps with stabilisation on the substitute medication, the initiation of positive changes and recovery (PHE, 2021).

## **Conclusion**

This chapter broadly aimed to present the properties of opioids, with a particular focus on illicit heroin and establish the reasons why some people may become dependent on the drug. Another key aim of the chapter was to consider the ways in which dependent individuals overcome their dependency on heroin. The chapter commenced with a description of cultivation of opium, the pharmacological properties of opium, the appearance of heroin, effects of heroin and various routes of administration. The legal status of heroin in the UK was defined. The incidence of people who use heroin was estimated through the analysis of data gathered from various methods. However, it is difficult to obtain the exact incidence of heroin because of the

illegality, stigma and secrecy surrounding the consumption of heroin. It is therefore anticipated that the actual incidence of heroin use is far higher than current estimates suggest.

Zinberg's (1984) *drug, set and setting* framework was used to explore the reasons why some people become dependent on heroin. The definition of dependency is complex because it is a) difficult to pinpoint the exact point of onset of dependency, b) not everyone who uses heroin persistently becomes dependent on heroin, and c) the onset of withdrawal in itself is not a reliable indicator of dependency. The *drug* factors of effects of heroin, tolerance and withdrawal and route of administration could contribute to the development of dependency. *Setting* factors such as imprisonment and homelessness could exacerbate the influence of the effects of drugs and enhance the likelihood of the development of dependency. The *set* factors of denial and impulsivity could facilitate the development of dependency. The *set* factor of denial could be related to the *setting* factor of stigma and prevent access to treatment. The use of heroin in response to negative moods (*set*)<sup>1</sup> could increase the probability of development of heroin dependence. The high incidence of childhood trauma and psychopathology (*set*) in the population of heroin dependent individuals could be indicative that heroin is used to soothe the effects of trauma and psychopathology. This could in turn increase the likelihood of onset of heroin dependency. The *setting* factors of drug using social network and living in disadvantaged areas could increase the likelihood of the development of dependency.

Research has suggested the important element of 'control' could differentiate between dependent and non-dependent users of heroin. For instance, non-dependent users of heroin were in control of their actions and maintained boundaries of control with peers. Research has established that a significant proportion of individuals overcome heroin dependency through 'natural recovery'. The discussion on 'natural recovery' highlighted the importance of qualitative interviews with people who have achieved recovery. This is because elicitation of factors that contribute to recovery could inform the development of new treatment interventions that could ultimately improve the wellbeing of heroin dependent individuals who are struggling to achieve recovery. One important finding of research on 'natural recovery' is that some people may struggle to achieve 'natural recovery' because of limited resources due

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<sup>1</sup> This explains how the *set* factor of negative mood is related to the use of heroin and the possible onset of dependency.

to disadvantaged backgrounds or absence of non-drug using needs. This suggests that some individuals may need the support of treatments such as OST to increase the availability of resources and achieve recovery. Both the pharmacological and psychosocial elements of OST could help with alleviation of withdrawal symptoms and help with increasing the number of resources that is needed to achieve recovery. This chapter concluded with a brief introduction to the concept of OST. The next chapter will describe OST in more detail by exploring aims, history, practice of OST and the effectiveness of OST.

## **CHAPTER THREE – Opioid Substitute Treatment**

### **Introduction**

It was noted in the previous chapter that dependence on heroin and other opioids can cause serious health and social problems (United Nations Office on Drugs and Crime(UNODOC), 2021; Home Office, 2021). While some people are able to stop using heroin naturally without recourse to professional support and treatment, many are not so fortunate. In this chapter, the discussion moves on to focus on the principal form of treatment available for people who have become dependent on heroin, namely opioid substitute treatment (OST). The chapter begins by defining OST and by reviewing the history and evolution of its use in the treatment of substance misuse problems. The philosophies underpinning this form of treatment are also considered. The chapter then moves on to examine the delivery of OST in practice, focusing where possible on the Welsh context. The chapter ends with a section in which the effectiveness of OST is considered. Given that the evidence base is so extensive, attention is focused on systematic reviews of the literature that have synthesised findings from across multiple evaluations of OST.

An important way of treating people with heroin dependence in the UK is OST (Public Health England (PHE), 2021). OST has two critical elements, namely the pharmacological and psychosocial components (PHE, 2021). The Clinical Guidelines (2017) specifically state that “Treatment for drug misuse should always involve a psychosocial component to help support an individual’s recovery.” (p.47).

### **3.1 Description of OST**

Heroin is an opioid, which means that it is derived from the opium poppy (see Chapter 2 for a fuller discussion). When heroin is used for a prolonged period and suddenly stopped, unpleasant withdrawal symptoms may occur, which often leads to continued consumption of heroin to alleviate the symptoms (US National Library of Medicine, 2019).

The pharmacological component of OST involves the substitution of illicit opioids with prescribed opioids, such as methadone or buprenorphine (PHE, 2021). This pharmacological component could involve either maintenance or detoxification (NHS, 2020). Maintenance therapy involves remaining on a stable dose of the substitute until the patient is ready to reduce

their dose (NHS, 2020). Detoxification also involves switching from use of heroin to an opioid substitute but is followed by gradual reduction of the substitute so that the individual becomes abstinent from both heroin and the opioid substitute (NHS, 2020).

The psychosocial component of OST aims to help people with stabilisation of prescribed opioids, to “make positive changes in their lives and recover from drug use” (PHE, 2021). The next section will review the history of OST, to help the reader understand how this treatment has evolved to its current form today.

### **3.2 Emergence and evolution of OST**

Before 1900 in the UK, people who used opium were largely perceived as having a bad habit or a vice (Berridge, 1980). However, in 1900, the concept of dependent opioid use or ‘addiction’ became recognised in the UK (Berridge, 1980). Most treatment for heroin dependency in the 1920s involved “the abrupt method of withdrawal” in institutions (Treadway, 1929). However, in 1926, Sir Humphrey Rolleston formed a committee with eight other physicians and after reviewing the evidence concluded that prescription of heroin or morphine to people dependent on these substances was appropriate for those for whom withdrawal was not possible because of increased risk of death or distress (Departmental Committee on Morphine and Heroin Addiction (Rolleston Committee), 1926). Furthermore, the Committee concluded that prescription of heroin was a legitimate form of medical treatment and would “enable the patients to lead useful and relatively normal lives” (Rolleston Committee, 1926, p.4). However, according to the Rolleston Committee (1926), at that time there were conflicting views among physicians on whether the goal was harm reduction (i.e., by maintaining patients on continued steady doses) or abstinence (i.e., by gradually reducing the dose).

Between 1959 and 1964, there was a significant increase in people who were dependent on heroin in the UK (Mold, 2004). The Ministry of Health (1967) faced the dilemma of drafting a policy that restricted the spread of addiction, while simultaneously ensuring the adequate provision of treatment to people who are dependent on heroin (Mold, 2004). A secretary of the Brain committee stated that treatment services should have a dual role i.e., treatment for people who want a cure (alleviation of withdrawal symptoms) and maintenance of heroin prescriptions for those who do not want to stop the use of the drug (Mold, 2004). However, the Ministry of

Health stated that these dual purposes of treatment services conflicted with each other (Mold, 2004). The Ministry of Health consulted drug experts for advice. The drug experts were divided in their opinions on how heroin dependent individuals should be treated. One perspective of some drug experts was that heroin dependent individuals who do not want to stop the use of the drug, should be offered ‘maintenance of heroin’ prescriptions. However other drug experts such as Dr. Bewley argued that methadone should be prescribed as a substitute to heroin to cure dependency (Mold, 2004). However, the Ministry of Health felt that the prescription of heroin on a maintenance basis should be continued because it would ensure containment and subsequently deter the growth of an international illicit drugs market (Mold, 2004). The Ministry of Health however stated that heroin should be prescribed in minimal quantities and the heroin dependent individual should be encouraged to accept withdrawal treatment (Mold, 2004).

As mentioned in the previous paragraph, Dr. Bewley advocated for the use of methadone in the treatment of heroin dependency. This raised the important question of when methadone emerged on the scene for the treatment of heroin dependency? Methadone was invented in 1937 in Germany by scientists in the Nazi conglomerate I G Farbenindustrie (Release, 2022). However, the potential use of methadone was rapidly abandoned because of extremely adverse side effects in early trials (Release 2022). It is worth mentioning that the early trials used extremely large doses of methadone by today’s standards (Release, 2022). Dole and Nyswander’s (1965) findings that prescription of methadone alleviated cravings and stopped the euphoria of heroin led to the development of large-scale methadone programmes in the US (Kleber, 2008). Similarly, in the UK, the increased incidence of heroin use and emergence of illicit imported heroin in the 70s, led to growing doubt amongst clinics of the efficacy of prescription of heroin as a treatment for heroin dependency (Preston and Bennett, 2014).

Clinical prescribing practices changed from prescription of heroin to prescription of oral methadone because of the therapeutic benefits, such as prescription of a non-injectable drug and long half-life (Preston and Bennett, 2014). One benefit of the long half-life was that methadone could be taken on a daily basis as opposed to every few hours (Preston and Bennett, 2014). Mitcheson and Hartnoll’s (1976, as cited in Preston and Bennett, 2014) found that methadone treatment was associated with a greater likelihood of achievement of abstinence from heroin, in comparison to heroin treatment. During this time, an increasing number of individuals were also starting to smoke heroin in the UK, which meant there was less demand

for injectable drugs (Preston and Bennett, 2014). Both the findings of Mitcheson and Hartnoll's (1976, as cited in Preston and Bennett, 2014) study and the transition to smoking of heroin, contributed to the increasing use of oral methadone in the UK (Preston and Bennett, 2014).

The search for an antagonistic alternative to methadone was driven by the high incidence of relapse associated with methadone (Campbell and Lovell, 2012). Reckitts and Colman (a pharmaceutical company) discovered buprenorphine in 1966, after spending ten years trying to produce an opioid compound with complex structures that retained the positive actions of morphine, but without the undesirable side effects of morphine (Campbell and Lovell, 2012; Release, 2020). Buprenorphine (trade name Subutex) was initially marketed as being advantageous to methadone because its partial agonist effect reduced the risk of respiratory depression (Release, 2020).

In 1999, buprenorphine was introduced in the UK to treat opioid dependency (De Wet, Reed and Bearn, 2005). The recommendation by the National Institute of Clinical Excellence (NICE) that buprenorphine should be a medication choice for treatment of opiate dependency, in addition to methadone meant that it was commonly used in treatment centres in the UK (Release, 2020). However, concerns about compliance with treatment, misuse and diversion of substitute medications and the burden of daily supervised administration of substitute medication initiated interest in the development of prolonged release medications (European Medicines Agency, 2018). In November 2018, buprenorphine depot injections (trade name Buvidal) were certified to be used in Europe (Neale, Tompkins and Strang 2019).

On 30 January 2020, the World Health Organisation announced that COVID-19 (a Coronavirus) was of international concern. There was little knowledge of how the virus spread and strict lockdowns were enforced. Concerns were raised about the vulnerability of people with substance misuse. The Welsh Government (WG, 2021) considered the provision of OST as an essential service during the pandemic. In 2020, the WG provided funding for Buvidal (a monthly injection) to be prescribed to a range of heroin dependent individuals, ranging from those with issues of homelessness to those stable on other forms of buprenorphine, such as Subutex and Espranor in Wales (Addiction Professionals, 2020). The provision of funding was based on the rationale that the injection would limit contact between staff members and heroin dependent individuals and thus reduce community transmission of the virus (WG, 2020; Kaleidoscope, 2020). Recently, Scotland has introduced buprenorphine implants which can be

inserted into the arm in a surgical procedure (Bussey, 2021). The effects of the implant lasts for six months and removes the requirement of OST patients to attend pharmacies or drug agencies on a regular basis (Bussey, 2021). Therefore, over time OST has evolved from the sole use of methadone in the 1960s to the use of buprenorphine in the late 90s and the more recent introduction of depot and implant formulations of buprenorphine.

### ***3.2.1 Evolution of psychosocial interventions and harm reduction approaches***

As long ago as 1920, the Rolleston Committee (1926) emphasised that prolonged aftercare was needed to strengthen willpower, alter mindsets of heroin dependent individuals and address the causative factors of dependency. In the 80s, the concept of ‘intermediate goals’ emerged within treatment services. This included goals such as: cessation of offending behaviour and stopping of injecting behaviour (as opposed to stopping use altogether; Strang, 1998).

In the late 80s, there were increasing concerns about the transmission of HIV that was occurring between drug users, through the practice of sharing injecting equipment (Strang, 1998). Furthermore, there was recognition that the transmission of HIV occurred through sexual intercourse and was spreading into the wider community (Strang, 1998). The emphasis on harm reduction was evident in the displays of posters that warned of the dangers of sharing needles and in the establishment of needle exchange programmes that targeted drug users who were not engaged with treatment services (Strang, 1998). Having explored the evolution of substitute medications, the early implementation of psychosocial interventions and the development of the harm reduction approach, the next section will describe in more detail the three components of the current practice of OST in the UK i.e., the pharmacological treatment of physical dependency of the drug, psychosocial treatment of the underlying issues of drug dependency and the harm reduction approach.

### **3.3 Pharmacological interventions**

Pharmacological interventions are used to target withdrawal symptoms, prevent relapse, sustain abstinence of illicit drug use, deter the occurrence of complications of drug use and reduce harms related with drug use (Lingford-Hughes et al. 2012). One form of pharmacological interventions is OST. Opioid substitute medication can be differentiated depending on their effect at the opioid receptors in the brain (Pathan and Williams, 2012).

Opioid substitutes can be described as agonists, partial agonists or antagonists (Pathan and Williams, 2012).

### 3.3.1 Methadone

*Fig.1 Methadone Hydrochloride*



Methadone is an opioid substitute that is widely used to treat opioid dependence in the UK (NICE, 2020). An estimated 650,000 individuals are prescribed opioid substitute medication in Europe in 2017 (European Monitoring Centre for Drugs and Drug Addiction (EMCCDA), 2019). Over two-thirds (63%) of substitution patients in Europe were prescribed methadone in 2017 (EMCCDA, 2019). Between 2018-2019, 1334 individuals received methadone and psychosocial interventions in Wales (PHW, 2020). The most commonly prescribed formulation of methadone is a clear green solution that is swallowed (Martindale Pharma, 2020; see Fig.1). Methadone tablets are less commonly prescribed but they are recommended if there is pregnancy-related nausea or proven intolerance to the methadone solution (Department of Health, 2017).

Methadone is a synthetic “full mu-opioid receptor agonist” (US National Library of Medicine, 2009; Stotts, Dodrill and Kosten, p.2). This means that methadone reacts with a receptor to generate a full response from that receptor (Pathan and Williams, 2012). Methadone triggers the same opioid receptors that are activated by other opioids such as heroin and opioid pain medications (National Institute on Drug Abuse (NIDA), 2021). This activation of the same receptors by methadone means that cravings for drugs are alleviated (NIDA, 2021). The full

‘agonist’ properties of methadone means that it activates opioid receptors more strongly than partial agonists (NIDA, 2021). Despite the same activation of opioid receptors as heroin, methadone activates the receptors more slowly than heroin (NIDA, 2021). This means that the treatment doses of methadone do not generate euphoria (NIDA, 2021).

Over time, patients can develop a tolerance to methadone, which means that they need an increased dose to achieve the same effect (Gutwinski et al. 2016). The full agonist properties of methadone (i.e. the intensity of its effect) coupled with the increased tolerance to methadone have been linked with the continued consumption of heroin ‘on top’ of methadone treatment (NIDA, 2021; Gutwinski et al. 2016; Kaleidoscope, 2020; NICE, 2020).

In the UK, methadone is a controlled medicine that must be prescribed by a physician (Misuse of Drugs Regulation, 2001). NICE (2020) recommends initial administration of 10mg-20mg of oral solution of methadone, with an increase of 5-10mg on a daily basis until the cessation of withdrawal symptoms. The effects of methadone are experienced 30 minutes after swallowing and the highest intensity of effects are felt three hours after administration. The half-life (i.e., the amount of time that it takes for the pharmacologic effect to decrease by half) of the initial dose of methadone is 12-18 hours with an average of 15 hours (The Department of Health, 2003). Continuous dosing on a regular basis is associated with an extension of half-life to around 24 hours (US National Library of Medicine, 2009). The quantity of methadone in the opioid dependent patient’s body is stabilised over a period of 3-10 days (US National Library of Medicine, 2009).

Common side effects of methadone include poor sleep patterns, nausea and vomiting, constipation, dry mouth, sweating, problems with sexual functions, menstrual difficulties in women and increase in weight, vertigo, headache, dizziness and drowsiness (US National Library of Medicine, 2009; NICE, 2020). Depressant drugs such as benzodiazepines and alcohol enhance the effects of methadone (US National Library of Medicine, 2009). Methadone patients are at increased risk from tooth decay and erosion from the use of the methadone sugary syrup (Nathwani and Gallagher, 2008). The poor oral health of methadone patients could also be attributed to factors such as reduced saliva (which increases the development of plaque), limited awareness of oral health, failure to brush teeth twice a day and increased consumption of sugar in comparison to the general population (Ma et al. 2012).

Administration of benzodiazepines (40mg of Diazepam) with methadone was related with rises in subjective ratings relating to strength of the effect produced by the drug and sedation, in comparison to the sole administration of opioids (Lintzeris et al. 2007). OST patients on an insufficient dose of methadone, could therefore use illicit benzodiazepines or abuse prescribed benzodiazepines, to maximise the effects of methadone. Zhong et al. (2019) explored the reasons for use of alcohol while engaged with methadone maintenance programmes and found that drinkers had lower doses of methadone. This suggested that alcohol could be used by people to help cope with insufficient doses of methadone (Zhong et al. 2019).

### ***3.3.2 Legal classification of methadone***

In the United Kingdom, The Misuse of Drugs Act 1971 categorises drugs as Class A, B or C depending on “the harm attributable to a drug when it is misused” (NICE, 2020). Class A drugs are perceived to have the most harmful attributes, when compared to Class B and C drugs. Methadone hydrochloride is a Class A drug under the Misuse of Drugs Act 1971. Illegal possession of methadone without a prescription could result in 7 years imprisonment, unlimited fine or both and supply of methadone could result in life imprisonment, unlimited fine or both (UK Government, 2020).

### ***3.3.3 Buprenorphine hydrochloride***

Like methadone, buprenorphine is an opioid substitute that is used to treat opioid dependency (University of Arkansas for Medical Sciences (UAMS), 2020). One form of buprenorphine is the tablet version, which is also known by the brand names of Subutex and Temgesic (NHS, 2020). Buprenorphine hydrochloride are uncoated light orange biconvex tablets, with an oval dimension of 5 x 8mm with ‘B’ on one side, as seen in Fig.2 (Accord-UK, 2021).

*Fig.2 Buprenorphine tablets (UAMS, 2020)*



Buprenorphine is a partial opioid agonist and is situated in the middle between opioid full agonists (methadone, LAAM) and opioid antagonists (naltrexone, nalmefene). In Europe, 34% of OST patients were prescribed buprenorphine in 2017 (EMCCDA, 2019). Between 2018-2019, 641 individuals received buprenorphine in Wales (PHW, 2020). The agonist properties means that individuals with opioid dependency experience a reinforcing subjective effect from the medication (UAMS, 2020). This effect is frequently described as “feeling normal”. If a high dose of buprenorphine is given to an opioid dependent individual who is maintained on an optimal dose of a full agonist, precipitation of acute withdrawal symptoms will be initiated. In these circumstances, buprenorphine will displace the full agonists from the mu receptors but does not generate the required amount of receptor activation. This results in a decline of the effect of the agonist and the initiation of withdrawal symptoms (UAMS, 2020). This ‘precipitated abstinence syndrome’ is harder to reverse because of the strong attraction between buprenorphine and the opioid receptor (UAMS, 2020). Therefore, precipitated withdrawal may happen when buprenorphine is initially administered, and opioid drugs are still present in the system (Department of Health, 2017). Buprenorphine therefore generates a barrier to any administration of opioids. This blocking effect is attractive to OST patients who want to stop their use of heroin (UAMS, 2020).

The average time for maximum plasma concentration following sublingual administration of buprenorphine is 1 hour but can range from thirty minutes to three and half hours (Welsh and Valadez-Meltzer, 2005). The half-life of buprenorphine is approximately 4-6 hours (Lorman, 2014). Despite this short half-life, the effects of buprenorphine are long lasting because of its strong attraction and comparatively slow detachment from the mu receptor (Lorman, 2014). Common side effects of buprenorphine include “arrhythmias; confusion; constipation; dizziness; drowsiness; dry mouth; euphoric mood; flushing; hallucination; headache; hyperhidrosis; hypotension with high doses (NICE, 2020).

### ***3.3.4 Legal status of buprenorphine***

Under the Misuse of Drugs Act 1971, buprenorphine is categorised as a Class C drug and Schedule 3 drug (Misuse of Drug Regulations, 2001) in the UK. Those in possession of buprenorphine without a prescription may be imprisoned for two years, given an unlimited fine or both (UK Government, 2020). Illegal supply or production of buprenorphine could result in 14 years imprisonment, unlimited fine or both (UK Government, 2020). According to the Misuse of Drugs Regulations 2001, a doctor can prescribe buprenorphine.

### ***3.3.5 Types of buprenorphine***

In addition to Subutex/Temgesic, buprenorphine is available in other forms including: Suboxone (buprenorphine-naloxone) Espranor (2mg or 8mg of buprenorphine; Specialist Pharmacy Service, 2017) and Buvidal (Department of Health, 2017; Specialist Pharmacy Service, 2017; Datapharm, 2020).

### ***3.3.6 Suboxone (buprenorphine-naloxone)***

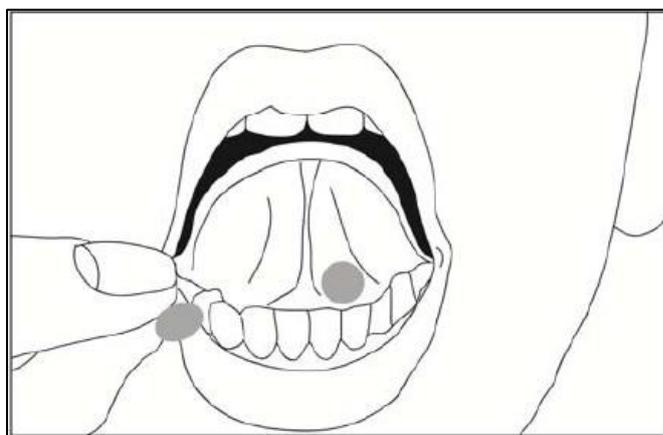
In response to increasing concerns about the misuse of Subutex, a new formulation of buprenorphine was developed that combined it with naloxone (an opioid antagonist that reverses an opioid overdose) (Department of Health, 2017). Suboxone are available in either the form of tablet or film. If buprenorphine-naloxone is taken as directed sublingually, the naloxone has low bioavailability and will not reduce the effects of buprenorphine. However, if the medication is used inappropriately by injection, the low bioavailability of naloxone means that withdrawal will be initiated (Lofwall and Walsh, 2014).

Research shows that the medicine is effective as lower levels of injection (misuse of the medication) were reported among those prescribed Suboxone than those prescribed Subutex. For instance, only 13% Suboxone patients injected their medication, in comparison to 28% of other buprenorphine patients (Larance et al. 2011). The lower levels of injection were attributed to anxieties surrounding naloxone and withdrawal (Larance et al. 2011).

### **3.3.7 Suboxone tablets**

The Suboxone tablet is placed under the tongue until it is dissolved (Ethypharm, 2019; Fig.3). This method of administration could allow for diversion as tactics such as storing the medication in the mouth and spitting it out when no one is looking have been used among populations of people who had formerly been in prison (Tompkins et al. 2009).

*Fig.3 Sublingual administration of buprenorphine*



Suboxone film are “orange, with the strength printed in white” and size of one film is 2.2cm x 1.3cm (Drugs of Dependence Unit, 2020; Fig.4). Suboxone films dissolve more rapidly in comparison to Suboxone tablets, as after 30-60 seconds the film becomes hard to remove (Drugs of Dependence Unit, 2020). This rate of faster dissolution could reduce the risk of diversion, in comparison to the pills (NPS Medicine Wise, 2011). The swift adherence of the film to the oral mucosa makes it difficult to remove and could therefore reduce the risk of diversion of medication (NPS Medicine Wise, 2011).

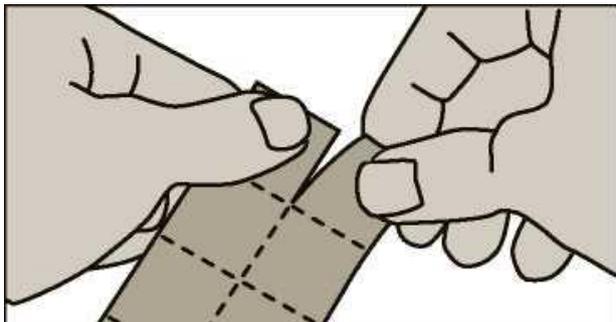
*Fig.4 Suboxone film with strength printed (Staticflickr, 2020)*



### **3.3.8 Espranor (Form of buprenorphine)**

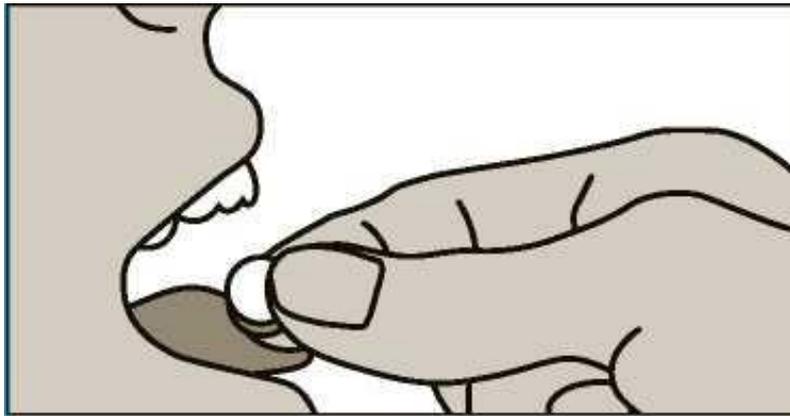
Espranor is a “freeze dried wafer (oral lyophilisate)” and has 2mg or 8mg of buprenorphine, (Specialist Pharmacy Service, 2017; Fig.5). Espranor has gelatin, unlike other forms of buprenorphine, which means that it not be suitable for vegetarians or vegans (Specialist Pharmacy Service, 2017).

*Fig.5 Espranor (freeze-dried wafer; i-medi, 2020)*



The bioavailability of Espranor is higher than other forms of buprenorphine medication. This means that the OST patient cannot be switched from a particular dose of Subutex to the same dose of Espranor (Specialist Pharmacy Service, 2017). The rapid dissolution of Espranor on the tongue in comparison to buprenorphine sublingual tablets is beneficial because it reduces supervision time of administration and deters misuse/diversion of the drug (Fig.6; Lynseng-Williamson, 2017).

*Fig.6 Administration of Espranor on the tongue (Martindale Pharma, 2020)*



### ***3.3.9 Buvidal (prolonged release solution of buprenorphine)***

Buvidal is a prolonged release solution of buprenorphine in a pre-filled syringe (Camurus, 2020). It is administered as “a weekly or monthly subcutaneous injection by a healthcare professional” (NICE, 2019, p.6). This subcutaneous administration of Buvidal means that the possibility of diversion is eliminated (Osborne et al. 2020). The pharmaceutical form of Buvidal is a yellowish to yellow clear liquid (Camurus, 2020; Fig.7). The weekly administration of Buvidal has a half-life of 3 to 5 days, while the monthly administration of Buvidal a half-life of 19-25 days (National Institute of Care and Excellence, 2022). Buvidal has complete bioavailability (“a measure of the rate and fraction of the a measure of the rate and fraction of the initial dose of a drug that successfully reaches either; the site of action or the bodily fluid domain from which the drug’s intended targets have unimpeded access”) (Camurus, 2020; Price and Patel, p.1). When Buvidal is injected, the interstitial aqueous fluid is absorbed by the fluid crystal formulation (Queensland Government, 2019). The fluid changes to a viscous liquid crystal which encloses the active substance (Queensland Government, 2019). This means that there is a “slow and consistent release” of buprenorphine over the month (Queensland Government, 2019). Qualitative interviews with fourteen Buvidal patients in England and Wales, showed that this constant stream of buprenorphine alleviated withdrawal symptoms (Parsons et al. 2020). The injecting method of Buvidal could result in pain with mild to moderate intensity at the injection site (Camurus, 2020; Parsons et al. 2020). Camurus (2020) recommended the rotation of injection sites on a regular basis.

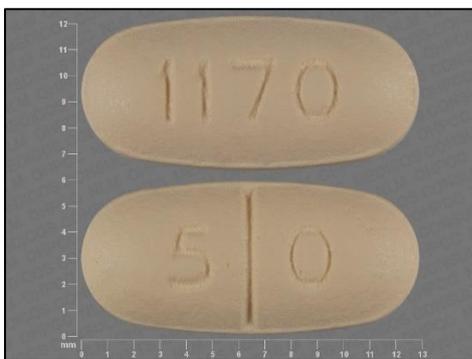
*Fig.7 Buvidal in pre-filled syringe (Ashtons Hospital Pharmacy Services, 2019)*



### **3.3.10 Naltrexone Hydrochloride**

In England, there were 11,000 to 14,000 prescriptions for naltrexone (NICE, 2007). There is no available data for the number of naltrexone prescriptions in Wales. Naltrexone hydrochloride are yellow, 50mg film coated tablets that are oval and biconvex in shape (Accord Healthcare Limited 2020; Fig.8). Naltrexone has a fast rate of absorption, metabolised by the liver and has a half-life of 4 hours (NICE, 2007).

*Fig.8 Image of naltrexone tablet (National Library of Medicine, Pillprogram, 2020)*



Naltrexone is an opioid antagonist with very little agonist activity (Accord Healthcare Limited, 2020). Naltrexone attaches to opioid receptors but generates no response, but simultaneously prevents an agonist such as heroin from attaching to that receptor (Pathan and Williams, 2012). The use of naltrexone is therefore related with the onset of withdrawal symptoms in opioid dependent individuals (NICE, 2007). Naltrexone is often used to help maintain abstinence from heroin (WG, 2011). The consumption of heroin with naltrexone will initiate prolonged opioid withdrawal with the possibility of severe medical consequences (Boyce, Armstrong and

Stevenson, 2003). The administration of naltrexone may therefore be inappropriate for individuals who are not motivated to stop their use of heroin (The Department of Health, 2017). After naltrexone treatment, the individual may also have reduced tolerance to heroin, which could in turn increase the risk of overdose (NICE, 2007).

### **3.3.11 Pharmaceutical heroin**

Pharmaceutical heroin is “a white to off-white, sterile, freeze-dried powder for reconstitution for injection” (Datapharm, 2020). Each ampoule has 100mg of diamorphine hydrochloride (Fig.9; Datapharm, 2020). Pharmaceutical heroin can be differentiated from street or illicit heroin, as it does not have impurities, diluents and adulterants (Klous et al. 2005). Pharmaceutical heroin was initially used for medical purposes as a cough suppressant to help patients with lung disease (Klous et al. 2005). As explained earlier, in 1926, the Rolleston Committee in the UK recommended prescriptions of heroin for heroin dependent individuals who had not succeeded in other treatments (Carnwath, 2010).

*Fig. 9 Ampoule of 100mg of diamorphine hydrochloride (The Pharmaceutical Journal, 2019)*



In order to prescribe heroin today, doctors need a Home Office License under the Misuse of Drugs (Supply to Addicts) Regulations 1997 (UK Government, 2020). Only 3% of the OST population (650,000) were prescribed heroin in Europe in 2017 (EMCCDA, 2019). Nowadays in the UK, pharmaceutical heroin is prescribed to only a small cohort of opioid dependent patients who have not previously benefitted from OST (Klous et al. 2005). Indeed, only 12.8% of OST patients were prescribed injectable diamorphine, in comparison to 85.6% who were prescribed injectable methadone in a drugs clinic in the Northwest of England (Sell, Segar and

Merrill, 2009). Furthermore, many heroin dependent individuals do not have access to prescription of heroin as a treatment option (Carnwath, 2010). Metrebian et al's (2002) study partially addressed the reasons for low incidence of prescriptions for heroin in the UK, by surveying a) doctors who had a licence to prescribe the drug and b) doctors who were eligible to have a licence. The absence of appropriate training, high cost, inadequate facilities and lack of evidence for efficacy of intervention were cited as reasons for not prescribing heroin (Metebian et al. 2002).

Middlesborough Heroin Assisted Treatment (HAT) is the UK's first heroin assisted treatment (HAT) programme (Police and Crime Commissioner for Cleveland, 2022). HAT is an option for people with a long history of heroin dependency and have failed to benefit from conventional OST (Police and Crime Commissioner for Cleveland, 2022). Participants attend the clinical twice a day, 7 days a week and the appropriate dose of prescribed heroin is decided by a medical professional (Police and Crime Commissioner for Cleveland, 2022; Home Office, 2021). After stabilisation on the appropriate dose, HAT should focus on cessation or reduction of illicit heroin use (Home Office, 2021). The heroin is self-administered with the supervision of medically trained staff at the treatment clinic (Police and Crime Commissioner for Cleveland, 2022).

### ***3.3.12 Legal status of pharmaceutical heroin or diamorphine***

Pharmaceutical heroin or diamorphine is categorised as a Class A drug under the Misuse of Drugs Act 1971. Possession of diamorphine without a prescription could result in 7 years imprisonment, unlimited fine or both (UK Government, 2020). Supply and trafficking offences of diamorphine could result in life imprisonment and/or an unlimited fine (Release, 2020).

### ***3.3.13 Choice of appropriate substitute medication***

At present, there is inadequate evidence to inform the recommendation that one form of substitute medication is more efficient than the other. Therefore, the Department of Health (2017) recommended that the OST patient's preference for a particular medication, previous benefits from medication, safety concerns, availability, interactions with drugs and practical factors such as availability of medication in local pharmacies must be considered when

choosing the appropriate substitute medication. Of particular importance, is that the full agonist properties of methadone and increased tolerance, could lead to habitual consumption of heroin or requirement for maintenance on increased doses of methadone. Similarly, the blocking effects of buprenorphine could be difficult for patients who are not ready to stop their use of heroin. The Orange guidelines stipulate that psychosocial interventions must be delivered in conjunction with OST as a component of the treatment package. The next section will explore how the delivery of psychosocial interventions is integrated with OST in drug treatment services.

### **3.4 Psychosocial interventions and OST**

Psychosocial interventions aim to initiate psychological changes by using unstructured support, simple motivational interviewing techniques and specialised psychological interventions (Department of Health, 2017). Heroin users who are stabilising on substitute medication need psychosocial support to resist the temptation of illicit use of heroin and related risky behaviours (Department of Health, 2017). Appropriate psychosocial interventions and a strong therapeutic alliance are needed for the occurrence of positive changes, while engaged with OST. Motivational interviewing (MI), Contingency Management (CM) and Social Behaviour Network Therapy (SBNT) are examples of specialised interventions that are used within drug treatment agencies (Department of Health, 2017). MI is used for affirmation of strengths and CBT strives to alter drug use and behaviours through the development of positive cognitions (Department of Health, 2017). CM involves the provision of rewards for non-drug using activities, such as take-home doses of OST (rather than pick-ups that require daily attendance at a clinic or pharmacy) for negative test results (Department of Health, 2017). SBNT helps with the development of non-drug using networks that can support patients on their recovery journeys (Department of Health, 2017).

The Department of Health (2017) emphasised the importance of rewards, retention in treatment avoidance of punitive responses and acknowledgement of progress in OST. The Department of Health (2017) also underlined the importance of consistency and clarity in the delivery of psychosocial interventions. The use of drug testing (to identify the presence/absence of illegal drugs) has also been recommended to support the delivery of psychosocial interventions. For instance, positive drug tests for illicit substances could be used to support MI through

discussion of barriers of change, identification of other forms of support or to change focus of treatment services to harm reduction (Department of Health, 2017). Similarly, CM programmes are recommended to reward goals such as attendance of appointments, achievement/maintenance of cessation of heroin use, cessation of injecting behaviour and/or abstinence from poly-substance use (Department of Health, 2017).

However, research has shown that the practices of delivering OST do not always conform with the Department of Health's (2017) emphasis on acknowledgement of progress, avoidance of punitive approaches and retention in treatment. For example, in Dennis's (2021) study of a drug agency in the UK, one service user explained that her positive drug test result had resulted in supervised consumption of medication by treatment services. The service user said she found this experience of supervised consumption of medication degrading and subsequently decided to leave treatment. Dennis's (2021) study therefore highlighted that the use of punitive approaches by treatment services (supervised consumption) in response to positive drug tests could contribute to termination of treatment. Strike and Rufo (2010) also explored the experience of drug testing through interviews with 18 workers, 64 OST patients and 12 physicians at a methadone maintenance treatment centre in Ontario, Canada. Some staff members believed that urine testing meant that OST patients were reluctant to admit the use of drugs and had also created an atmosphere of surveillance that was destructive to the therapeutic relationship (Strike and Rufo, 2010). It has been questioned whether the adoption of person-centred and non-directive ethos recommended by the Department of Health (2017) is possible in settings, such as OST, that limit the autonomy of the patient (Ashton, 2005).

### **3.5 Delivery of OST**

The next section discusses the practice of delivery of OST, as this provides important context and background, prior to the evaluation of efficacy of treatment services. Given that this research on which this thesis is based was conducted in Wales, this thesis will focus on the delivery of OST in Wales.

#### **3.5.1 Setting**

As noted above, OST should involve the delivery of pharmacological and psychosocial interventions to treat opioid dependence (EMCCDA, 2019). OST in Wales can be delivered in

a number of settings such as primary care, specialised drug clinics, day programmes, criminal justice programmes, prisons and pharmacies (WG, 2011).

The voluntary, third or charity sector describes organisations whose main aims are to generate social impact, as opposed to profits (Reach Volunteering, 2022). Area Planning Boards (APB) were established in 2010 in Wales to deliver the Welsh Substance Misuse Strategy (WG, 2017). APBs also have the responsibility of the development, delivery and improvement of efficient substance misuse services (Cardiff and Vale University Health Board, 2022). Examples of substance misuse services delivered within the voluntary sector in Wales include Gwent Drug and Alcohol Service (GDAS), Dyfed Drug and Alcohol Service. Healthcare Inspectorate Wales (HIW) inspects and regulates healthcare in Wales, to ensure that people in Wales are receiving good health care (HIW, 2018). However, most substance use services in the voluntary sector provide Tier 1 and Tier 2 services which means that “they do not fall under the legal remit” of either the Care Inspectorate Wales or HIW (HIW, 2018; p.11).

The statutory sector is involved in the delivery of substance misuse services either by the NHS or independent health care services (HIW, 2018). Gwent Specialist Substance Misuse Service (GSSMS) is one example of a statutory NHS specialist substance misuse service that offers harm reduction interventions (e.g. Needle and Syringe Exchange Programme, harm reduction clinics, provision of naloxone) and specialist drug support (e.g. OST, alcohol detoxification, alcohol related brain damage assessment, treatment services for pregnant women experiencing difficulties with drugs). Pobl Cymru (2021) is an example of an independent organisation that offers structured group work, peer support, counselling and volunteering opportunities to people experiencing difficulties with drugs in Cardiff and the Vale of Glamorgan.

Community pharmacies play an important role in the supervision and dispensing of prescribed substitute medication in Wales as well as the provision of harm reduction equipment such as needles and syringes (Healthcare Inspectorate Wales (HIW), 2018). While pharmacies play an important role in the provision of OST, consultations with staff members, service users and area planning board representatives identified concerns around inflexibility of opening times, limited privacy, lack of dignity and potential breaches of confidentiality (HIW, 2018). UK

policies have generally encouraged GPs to be involved in the treatment of opioid dependent individuals and this is reflected in the Welsh substance misuse framework, which emphasises that GP shared care schemes and GP led prescribing could increase accessibility to OST (WG, 2011; Strang et al. 2005). Between 1985 and 2005, there has been a significant increase in GPs who prescribed opiate substitute drugs in England and Wales i.e., half of the doctors who had seen opioid dependent patients in the last four weeks had prescribed substitute medication in 2001, compared to about 31% in 1985 (Strang et al. 2005). Willott (2006) attributed this increase in the prescription of substitute medication by doctors in 2001 to improved specialist training in substance use for doctors (such as courses mapped to the Drug and Alcohol National Occupational Standards).

However the latest data suggests that the provision of prescribed substitute medication for drug dependency is very patchy across Wales. There is no publicly available data of the number of people who are currently receiving shared care in Wales. However, Stats Wales (2021) provides information on the number of people discharged into GP led prescribing. According to Stats Wales 2021, 119 people were discharged into GP led prescribing in 2020/2021, which is a 30% increase since the last year. However this is only a small proportion (1%) of the population who accessed substance misuse treatment in Wales i.e. in 2019/2020, 24,000 people were referred to substance misuse services, more than 18,000 individuals were assessed and 16,000 commenced treatment (WG, 2021; PHW, 2020). This suggested that the provision of substance misuse treatment by doctors in Wales is very limited.

### ***3.5.2 Interventions to reduce misuse/diversion of medication***

Recent research in Wales has shown that misuse and diversion of substitute medication is common amongst people who use drugs (May et al. 2020). In 2019, there were 177 deaths related to methadone poisoning in England and Wales (Statista, 2021). In Wales in 2019, there were 56 deaths that involved opioids other than heroin/morphine (PHW, 2020). These deaths may include those who are prescribed methadone (who may overdose through using on top) as well as people who have not been prescribed methadone. Of particular concern is the number of child victims, especially given that children under the age of four were found to be more likely to die (16 of 28 cases) from unintentional poisoning with methadone than any other prescription drug in England and Wales (Anderson et al. 2016). One reason for the high

incidence of methadone related accidental deaths, could be that methadone patients are “potentially least able to guarantee it will not be accessible to young children”, presumably because of their levels of intoxication (Anderson et al. 2016, p.655).

Concerns such as these have led to the practice of supervised consumption to reduce the risk of diversion and accidental ingestion of substitute medication. Consumption of medication is normally supervised by the community pharmacist or nurses employed by specialist drug agencies at the site of the drug agency. The Department of Health (2017) recommended that the duration of supervised consumption should be based on individual risk assessments, to reduce the risks of accidental ingestion (Department of Health, 2017). In a qualitative study that explored the experience of delivering and receiving OST from the perspectives of patients and staff, it was found that supervised consumption conferred stability, allowed for the establishment of a structured routine and the development of therapeutic relationships (Notley et al. 2013).

Despite these benefits of supervised consumption, Anstice Strike and Brand’s (2009) qualitative study of methadone patients in Canada found that supervised consumption can sometimes be a stigmatising experience and detract valuable time away from psychosocial work (Anstice et al. 2009; Kaleidoscope, 2020). For instance, some OST patients stated that the practice of consumption of methadone at the pharmacy was an embarrassing experience, because it attracted attention from the public (Anstice et al. 2003). In recognition of the possible negative consequences, the Department of Health (2017) recommended the practice of unsupervised consumption as an incentive to promote progress in treatment. OST patients in Notley et al’s (2014) study reported that unsupervised consumption enhanced flexibility, reduced stigma, allowed OST patients to consume medication at the optimal time that could alleviate withdrawal and was perceived as a reward. However, professionals and OST patients in Notley et al’s (2014) expressed concerns around chaotic lifestyle, dishonesty, illicit heroin use, risks of accidental ingestion and diversion of medication. Notley et al. (2013) stated that the tension between the benefits of unsupervised consumption and the risks of unsupervised consumption could be resolved through the introduction of shorter periods of supervision or a transition to less regular supervision over time (Notley et al. 2013). However, Notley et al. (2013) acknowledged that reduced supervision could have a detriment impact on the

therapeutic relationship. Notley et al. (2013) conclude that more research is needed on the varying schedules of supervision.

To reduce the risk of accidental ingestion and diversion, treatment services have encouraged the safe storage of substitute medication in secure boxes (see Fig.10). In the UK there is no legal obligation for the provision of methadone in a child resistant container (Mullin et al. 2008). However, the Department of Health (2017) recommended that OST patients should be given information on the storage of the prescribed medication away from the reach of children.

*Fig.10 Storage box for methadone hydrochloride (UK Medication Safer Storage, 2020).*



Mullin et al. (2008) conducted an anonymous questionnaire survey that explored the safe storage of methadone among 174 methadone patients attending services in Staffordshire. In addition, community pharmacies were contacted by telephone to enquire about advice given regarding safe storage of methadone. The research found that only a small minority (28.2%) of methadone patients remembered receiving advice about safe storage of methadone and that the vast majority (87.9%) stored methadone in an unlocked location (Mullin et al. 2008). Only 8 pharmacists (28.6%) stated that they gave information about safe storage to OST patients and some pharmacists believed that it is the pharmacist's decision if they gave advice or not (Mullin et al. 2008). Mullin et al. (2008) recommended that treatment services should regularly remind OST patients about the importance of safe storage every few months. OST patients should also be given information on safe storage at the transition stage from supervised consumption to unsupervised consumption (Mullin et al. 2008). Health professionals should also use verbal/written material and targeted text messages to convey the importance of safe storage of prescribed medication (Mullin et al. 2008).

More encouragingly, similar survey research conducted in Scotland found that 80% of OST patients stored their medication out of reach from children and in a secure container (Williams et al. 2009). The discrepancy between Mullin et al's (2008) and William et al's (2009) findings could be attributed to local initiatives that involved the sticking of additional warning labels on methadone bottles and Scottish guidelines that aimed to protect children living with parents who misused substances (Williams et al. 2009). This suggests that treatment and drug policies have the potential to enhance safe storage practices, while promoting the autonomy of OST patients.

To summarise, the risks of accidental ingestion, particularly among children, has highlighted the need for treatment services to minimise the risk of diversion (e.g., through supervised consumption). However, these practices are a double-edged sword as while they may protect against diversion, they have been found to threaten the autonomy of the OST patient and perpetuate stigma.

### ***3.5.3 Pragmatic and operational factors in the delivery of OST***

My previous experience as active treatment worker at the drug agency where I intended to interview participants, meant that I was closely acquainted with the working practices of the organisation. The drug agency has operational bases in Newport, Monmouthshire, Blaenau Gwent, Caerphilly and Torfaen. Referrals are normally taken via the central phone number and referrals can come from various sources such as self, doctors, social workers, family members etc. The new OST patient is normally matched to the appropriate keyworker based on the geographical area by the team leader. In Newport, medication is usually dispensed at the site of the agency in a booth. Once the patient arrives, he/she is identified using a picture or fingerprint and the dispenser is activated to generate the right dose of methadone (Methameasure Limited, 2022; Fig.11). The dose is dispensed, and records are updated (Methameasure Limited, 2022). Other types of substitute medication such as Subutex and Buprenorphine are also administered at the base. However, in other localities, medication is usually dispensed at the local pharmacy.

*Fig.11 Methadone dispensing machine (Methameasure Limited, 2022)*



The opening times of bases are normally 9-5 from Monday to Friday. In Newport, the drug agency is opened late on one weekday. The opening times of local pharmacies vary, and some pharmacies are open on the weekends. This means that medication can only be dispensed within these opening times of the pharmacies and drug agencies. The lack of out of hours support during weekends and evenings, may mean that OST patients do not get support during crises and are at increased risk of relapse or overdose during these times (HIW, 2018).

Most of the venues at the drug agency have both clinics, counselling rooms and needle exchange facilities. The venue in Torfaen has a garden, art room and kitchen which both OST patients and staff can access. The keyworker normally attends doctor appointments with the OST patient. If the keyworker is unable to attend, he/she is normally required to submit a written summary of the progress of the OST patient to the doctor. This is because OST patients normally see their keyworker on a more frequent basis i.e., weekly or fortnightly. OST patients are also required to see the nurse on a monthly basis and often see the doctor every 2-3 months. As mentioned earlier, urine or saliva samples are tested regularly for the presence of drugs (Department of Health, 2017). Treatment contracts are used in drug agencies when opiate users are not perceived to engage in problematic behaviour that is non-compliant with social norms (Bacon and Seddon, 2013) If an OST patient consistently fails to attend appointments, he/she may be placed on a 'behavioural treatment 'contract for a specified time period by the doctor, keyworker and nurse. The OST patient is required to sign a contract that he/she will attend appointments. Failure to attend appointments could result in detoxification of substitute medication, but the OST patient can still access psychosocial support from treatment services.

### **3.6 Prevalence of OST and characteristics of the OST population**

Having examined what OST looks like in practice, this section will explore the prevalence of OST with a particular emphasis on Wales. The UK has one of the largest populations of people in opioid substitution treatment in Europe (EMCCDA, 2019). The most recent data show that in 2017 654,000 individuals in the European Union received OST. Of these, 149,420 were registered in treatment in England and Wales (EMCCDA, 2019). This means that UK is second only to France, which has 178,655 individuals in OST (EMCCDA, 2019). Between April 2020 and March 2021, there were 275,896 individuals in contact with substance misuse treatment services in England (Office for Health Improvement and Disparities, 2021). The Office for Health Improvement and Disparities (2021) found that 140,863 individuals were in treatment for opioids i.e. over half of the overall treatment population in England (51%). This means that opioid users form the greatest proportion of the treatment population in England.

Of those individuals who were in continuous treatment in England and Wales, (i.e., those who were in treatment at the beginning of the calendar year when data were collected), nearly three-quarters (71%) stated that heroin was their primary substance (Focal Point, 2021). The proportion of people starting treatment (50%) is lower than the proportion of individuals in continuous treatment (71%), which suggests that there is a significant proportion of OST patients who have been engaged with treatment for more than a year.

Between 2019-2020, there were 18,184 assessments within substance misuse services (PHW, 2020). Opioids represented the greatest proportion of assessments at 4,288 (23.6%; PHW, 2020). Individuals who use alcohol problematically form the largest treatment population (8,161 individuals; WG, 2019). Heroin is a distant second as between 2018-2019, 2,809 individuals were in treatment for problematic use of heroin (WG, 2019). Evidently, the majority of people currently in treatment for substance misuse related problems in Wales (and England) are people who use heroin.

Importantly, while there are many people in Wales receiving OST, research has shown that there are many ‘problematic opioid users’ who are not in treatment. Problematic opioid use is defined by Public Health Wales (PHW) as “injecting drug use or long duration/regular use of opioids” (PHW, 2018, p.89). Using the capture-recapture method, PHW (2018) estimated that there were approximately 25,000 problematic opioid users in Wales at that time. This capture-

recapture method involved the triangulation and analysis of substance misuse data (police arrests, engagements with drug intervention programmes, assessments by drug treatment agencies, admissions to hospitals and access to needle exchange programmes) gathered from health, treatment and criminal justice agencies to produce an estimate of the size of the opioid using population not in contact with services (PHW, 2018). This is particularly important for this research project, given that the capture-recapture method is likely to include those who have never been in treatment but also those who have dropped out of services. The study also found that of those people who started treatment for heroin use in Wales, the majority were men (1,982 compared with 827 women) (WG, 2019). This suggested that females are underrepresented in treatment services.

On entry into treatment, all individuals are assessed by a key worker to identify their needs and to develop a care plan. In 2018, nearly 17% of all assessments (drugs and alcohol) by substance misuse treatment agencies in Wales were in respect of people whose primary substance was Heroin (WG, 2019). In Wales, Gwent had the highest rate of assessments for heroin use at 102 per population of 100,000 compared with a low of 60 per 100,000 in Powys (WG, 2019). It is unknown if this high rate is reflective of a high incidence of heroin use in Gwent and/or if people in Gwent are more likely to access treatment services for some reason (e.g., ease of access, perceived effectiveness).

In terms of the socio-demographic profile of people in treatment in Wales, the median age of clients assessed in 2018-2019 for use of heroin was 37 (WG, 2019). This was considerably older than users of other drugs. Indeed, the median age of clients assessed for cannabis and cocaine problems were 24 and 29 respectively (WG, 2019). Furthermore, 59% of those in continuous treatment for heroin use in England and Wales were aged 40 or over (Focal Point, 2021). This suggests that there is a cohort of ageing heroin users within OST (Focal Point, 2021). Focal Point (2021) stated that people experiencing difficulties with opioids generally spend longer (the average period was not specified) in treatment, in comparison to individuals who are in treatment for other drugs. Dame Carol Black's (2020) recent review of drugs showed that 1 in 6 opioid users in England have been engaged with treatment for more than ten years. Similarly, recent statistics in Wales showed that the average length in treatment at a drug agency for heroin users in March 2022 was 970.31 days, compared to 246.80 days for alcohol use (McNeil, 2022). The Advisory Council on Drug Misuse (ACDM, 2019) also recognised

that this cohort of long-term OST patients have complex needs and are struggling to complete treatment.

To recapitulate, statistics have shown that OST patients represent a significant proportion of the treatment population and that OST patients are an ageing cohort of whom many have been in treatment for long periods. The above discussion highlighted that a significant proportion of the treatment population consists of opioid users who have been engaged with OST for a long period. Dame Carol Black (2020) stated that the pressing needs of this long-term OST population, has resulted in the neglect of the treatment of other cohorts of patients within drug treatment services. The high incidence of OST patients who have been in treatment for a long period within drug treatment services raises the important question of the efficacy of OST in improving the wellbeing of the OST patient.

One of the key aims of the Welsh Substance Misuse Strategy is to “reduce the harms caused by substance misuse to the individual and wider society” (WG, 2019, p.5). The purposes of OST are to either decrease the consumption of illicit opioids or to completely stop the use of illicit opioids (PHE, 2021). The WG (2019) uses Key Performance Indicators (KPIs) to assess the performance of substance misuse agencies and to determine if these aims of OST are being met. Fig.12 shows a description of the KPIs used in Wales.

Fig. 12 Key performance indicators of substance misuse treatment agencies (WG 2019 and PHW 2020)

Measure	Rationale	Indicator of success	Welsh Benchmark
<i>Relevant and appropriate service-increase engagement</i>	Relevance of service to clients' needs is a measure of stability	Number of clients that do not attend. 'Did not attend or respond to follow up contact' is defined as the treatment provider has lost contact with a client without a planned discharge and attempts to re-engage the clients have not been successful (WG, (2020); p.5).	Red $\geq$ 30%, Amber 20.1 - 29.9%, Green $\leq$ 20%
<i>Engagement</i>	Rapid contact is related with better treatment outcomes	Waiting time of less than 20 days between referral and treatment	Red $\leq$ 70%, Amber 70.1 – 79.9%, Green $\geq$ 80%
<i>Impact services has on reduction of drug use</i>	Assessing this outcome is important to analyse the efficacy of treatment programmes	Substance misuse is reduced/or remains the same between entry and exit TOPS review	86.5%
<i>Enhancement of quality of life</i>	Assessing this outcome is important to analyse the efficacy of treatment programmes	Quality of life is enhanced/or remains the same between entry and exit TOPS review	84.2%
<i>Completion of treatment</i>	Assessing this outcome is important to analyse the efficacy of treatment programmes	Number of treatment episodes closed as 'treatment completed' Treatment completed is described as being abstinent from problematic substance or by reaching goalagreed at start of treatment	76.9%
<i>Testing of blood borne viruses</i>	WG to meet WHO's target of elimination of HBV and HCV by 2030	All clients in treatments must be tested at least every 12 months	50% by 2020 and going up to 100% by 2030

### **3.7 Treatment philosophy**

Drug treatment providers in the UK have primarily used either harm reduction or abstinence-based approaches to deliver treatment services (McKeganey et al. 2004). Recently the recovery movement also gained momentum in the UK during the time of the Global Financial Crisis (Best et al. 2017). Exploration of the concepts of harm reduction, abstinence and recovery are important for this research, because they are relevant to the delivery of OST.

#### **3.7.1 Abstinence**

DrugWise (2017) describe abstinence as an approach that can be used by “drug or alcohol treatment programmes that aim to help the person stop using drugs or alcohol for the rest of their lives.” This philosophy of abstinence has strong roots in American history and is an important doctrine of Alcoholics Anonymous which was founded in 1935 (Mignon, 2014). One example of an abstinence-based organisation is Narcotics Anonymous (NA) United Kingdom, which is a non-profit mutual aid peer group (NA, 2021). NA advocates for abstinence from both drugs and alcohol because “complete and continuous abstinence provides the best foundation for recovery and personal growth” (NA, 2021). In relation to OST, PHE (2021) stated that one of the purposes of OST is to completely stop the use of illicit opioids.

In England, Labour Government’s *Tackling Drugs Together to Build a Better Britain* (1998) strategy was focused on harm reduction as it aimed to reduce injecting behaviour, lower crime rates and increase engagement with treatment services (Ashton, 2015). By contrast, the Social Justice Policy Group’s (2007) policy recommendations to the Conservative Government in their *Breakthrough Britain Ending the costs of social breakdown* paper, emphasised that the indefinite prescription of methadone has detrimentally affected the rehabilitation of people who are dependent on drugs. The Conservative Government’s *Drug Strategy 2017* also emphasised that the aim of the strategy was to help people stop the use of drugs. More recently, the UK Drug Strategy 2021 states that persistent drug use will be addressed by a punitive approach (HM Government, 2021). The strong quote “We will not hesitate to ensure repeat offenders face consequences. At this stage nothing is off the table” is evidence of the punitive approach (HM Government, 2021, p.55). This raises the important question of how the long-term OST population who are struggling to achieve abstinence from heroin will be affected by the new approach.

The devolution of Wales in 1998 has allowed for the development of autonomy and use of harm reduction approaches in the drafting of drug policies (Brewster and Jones, 2018). Nevertheless, elements of an abstinence-based approach are apparent in the delivery of treatment services in Wales too. In Wales, the KPI of ‘completion of treatment’ as a measure of success in treatment (see Fig.13) could be considered to be consistent with the abstinent approach and perhaps indicative of Governmental intention to reduce costs. Treatment exits could be indicative of a desire to reduce costs because it was presumed that treatment leavers will leave treatment, gain employment and promote economic growth (Davies and Ashton, 2016). Furthermore, increased incidence of treatment exits will mean that public spending can be redirected to other areas (Davies and Ashton, 2016). However the problem is that not all individuals are capable of achievement of these ambitious goals of leaving treatment and gaining employment for a variety of reasons such as mental health (Best, De Awlis and Burdett, 2017).

Wales has maintained steady funding from 2011-2014 (£22.51 million in 2011; £27.54 million in 2012; and £26.59 million in 2013 from the Substance Misuse Action Fund) although there has been a reduction in ‘real’ terms considering inflation (Real Reporting Foundation, 2021). However, in 2019/2020, £2.4 million additional funding was provided by the WG to fund substance misuse treatment services in Wales (WG, 2019). The increase in funding has been welcomed by drug experts, but it was perceived that additional funding was needed to address poly-drug use by heroin users and reduce risk of overdose (Holloway, 2019).

Research has shown that the group of individuals who are unable to or unwilling to achieve abstinence are at the highest risk of offending, overdose and dropping out of treatment (Transform Drug Policy Foundation (TDPF), 2015). Under an abstinence based approach, patients can be exited from treatment before they are ready, which can then lead to return to risky patterns of drug use and subsequently an increase in drug related deaths (Kalk, 2018; McKeganey, 2011; Cornish et al. 2010).

### **3.7.2 Harm reduction**

Harm reduction is based on the philosophy that “many people throughout the world are unable or unwilling to stop using illicit drugs” (Harm Reduction International (HRI), 2021). The harm

reduction approach aims to prevent drug-related deaths and protect people who use drugs from drug-related harm (HRI, 2021). OST is an important form of harm reduction because it is associated with reduction of illicit opioid use, reduced risk of overdose, lower risk of mortality, decline in injecting behaviour and sharing of injecting equipment (NICE, 2007). This decline in injecting behaviour and risky behaviours are influential in the reduction of BBV infections such as HIV and Hepatitis (PHE, 2021).

Naloxone is administered when a person is unconscious or unresponsive due to a heroin overdose (Prenoxad Injection, 2019). When naloxone is administered it attaches to opioid receptors and blocks the effects of opioids for approximately 20 minutes. This allows an individual to regain consciousness and also offers a window of opportunity for emergency services to be contacted (PHW, 2018). The WG introduced the Take Home Naloxone (THN) project in 2009 to reduce drug related deaths (PHW, 2018). After a successful pilot demonstration project, the THN scheme was rolled out across Wales in 2011. In Wales there is more emphasis on provision of Naloxone to prevent opioid overdoses, while in England the distribution of naloxone is more intermittent (Brewster and Jones, 2018). This suggests that Welsh drug policies are based more on the elements of harm reduction. Furthermore, Barod in Wales has recently increased accessibility to Naloxone through provision of the ‘click and deliver service’ (Barod, 2020). This service allows individuals at risk of overdose, family/friends, professionals and members of the public to request naloxone to be delivered to their home address (Barod, 2020).

Provision of needle exchanges are another way in which Wales have embraced the principles of harm reduction. The aims of needle exchanges are to deter the transmission of BBV through needles or sexual relationships, ensure safe disposal of needles, increase awareness of risks related with injecting and provide harm reduction advice (WG, 2011). In Wales, there are 57 specialist needle exchange services and 217 community pharmacies (PHW, 2020). Between 2019-20, there were 142,190 interactions which is a decline of 4% since the previous year. This decline was attributed to reduction of services during the COVID-19 pandemic (PHW, 2020). Between 2017-2018, 48% of individuals in Wales, attending a needle exchange stated that they used opioids (PHW, 2018). Most of these individuals were aged between 35-39 and the people over 50 has increased from 6.5% to 10.4% (PHW, 2018).

### **3.7.3 Recovery**

As discussed earlier in this chapter, in response to the AIDS epidemic in the 80s, treatment services focussed on reducing harm to both the individual and society. However, around 2005, the term ‘recovery’ started to gain prominence within the field of substance misuse and there was increasing focus on societal integration (UK Health Security Agency, 2013). The *2010 Drug Strategy* made explicit reference to the term ‘recovery’ which included an emphasis on wellbeing, contributions to society and citizenship. The Betty Ford Institute Consensus Panel (2007, p, 221) defined recovery as “a voluntarily maintained lifestyle composed characterised by sobriety, personal health, and citizenship.” It is important to explore how recovery is perceived by individuals with lived experience, to ensure that have a ‘voice’ in issues that are directly relevant to them. Laudet’s (2007) study addressed this issue and explored how the definition of ‘recovery’ is perceived by participants with heroin or crack dependency. Participants stated that recovery means more than abstinence and “it is experienced as a bountiful new life, an ongoing process of growth, self-change and of reclaiming the self” (Laudet, 2007, p.243). In Wales, Cyfle Cymru which supports people experiencing difficulties with drugs to gain employment, is a good example of the benefits of implementation of the recovery model in Wales (TDPF, 2015).

Best, Irving and Albertson (2016) stated that the concept of ‘recovery’ has two distinctive branches. One branch is based on the AA philosophy that recovery is triggered by the achievement of abstinence and dependent individuals will need lifelong support (Best et al. 2016). The other perspective is based on the Therapeutic Community’s approach that once individuals have achieved ‘recovery’ they have become ex-addicts and will no longer need support. Over the years, these different underlying philosophies has resulted in different interpretations of the term ‘recovery’ (Best et al. 2016).

The Conservative Government in England responded to the economic crisis from 2007 to 2009 through the introduction of austerity measures (Davies and Ashton, 2016; Best et al. 2017). These austerity measures established the platform for the interpretation of ‘recovery’ that emphasised achievement of abstinence, treatment exits and gaining employment in England (Davies and Ashton, 2016; Best et al. 2017). This suggested that the English Government interpreted ‘recovery’ to mean the achievement of abstinence from drugs.

Conversely, the Welsh Government (2014) recognised that controlled use of drugs can be considered as recovery. In Wales recovery is defined as “a process in which the difficulties associated with substance misuse are eliminated or significantly reduced, and the resulting personal improvement becomes sustainable” (Welsh Government, 2014, p.5). This definition of ‘recovery’ emphasised the elimination of difficulties with substance use, as opposed to abstinence from the drug. Despite this harm reduction based interpretation of ‘recovery’ by the Welsh Government, the description of ‘exit from treatment’ as an indicator of treatment success (KPI 5) and the narrow interpretation of recovery as the achievement of abstinence within Welsh treatment services does not sit comfortably with the principles of harm reduction (TDPF, 2015). This emphasis on abstinence within the recovery agenda is problematic for individuals who are not able to or do not want abstinence (TDPF, 2015). In practice, the misinterpretation of the recovery agenda by prescribers and OST patients to mean ‘abstinence’ could result in premature detoxification of medication and relapses (Kalk et al. 2012). However, it is possible that this drive for completions is less about a drive for abstinence and more about the need to reduce costs and address the ethical issues of indefinitely supporting patients on OST (Magura and Rosenblum, 2001).

While harm reduction remains at the heart of Welsh drug policies, the focus on exits from treatment in Wales questions whether maintenance of substitute medication (i.e., harm reduction) can still be considered as a measure of treatment success. Furthermore, the misinterpretation of the recovery agenda as ‘abstinence’ by treatment services has resulted in premature detoxification and lapses. The next section will evaluate the effectiveness of OST, in light of the changing definitions of success in treatment.

### **3.8 Evaluation of effectiveness of OST**

Kratochwill and Bergen (1990) stated that treatments are evaluated to ascertain (a) whether the objectives of treatment have been achieved, (b) if the treatment has been effective and (c) whether the treatment is acceptable to OST patients and staff members. To identify evaluations of OST, searches of PubMed (a database that is known to have relevant research publications) were undertaken. The search term ‘Effective AND methadone’ on PubMed yielded 8,898 results, while the search term ‘effective AND buprenorphine’ resulted in 5,374 results. Evidently, there are a large number of research articles that have explored the effectiveness of

OST. Given the size of the evidence base, a revised search was undertaken that involved searching for systematic reviews of the literature on the effectiveness of OST. This search yielded 163 hits on PubMed and 10 hits on the Cochrane Library (a database of relevant research publications), which are summarised in the sections below. The Cochrane Library (2022) states that “a systematic review attempts to identify, appraise and synthesize all the empirical evidence that meets pre-specified eligibility criteria to answer a specific research question.” The Cochrane library was also used to search for systematic review that explored the efficacy of OST, which yielded 10 results.

Randomised controlled trials (RCT) s are the ‘gold standard’ of effectiveness research, while systematic reviews of RCTs are deemed to be the ‘gold standard ‘in the synthesis of effectiveness research’ (Torgerson, 2003). RCT can be described as the random assignment of similar individuals to either the experimental group or a control group (NICE, 2022). Members of the experimental group are exposed to the intervention being tested while members of the control group are exposed to an alternative intervention, placebo or no intervention (NICE, 2022). Quasi experimental designs are similar to RCTs in that there are experimental and control groups. However, in a quasi-experimental design, assignment into groups is not random. Instead, assignment is based on self-selection or subjective assignment of the experimenter (Cook, 2015).

Some systematic reviews present findings in a narrative review format while others synthesise the findings quantitatively using meta-analyses. “Meta-analyses is a statistical technique that allows the results of independent studies to be combined to research related hypotheses” (Mignon, 2014; p.2). The efficacy of treatment is usually assessed by measuring changes in use of substances and or related problems, such as offending or mortality (Mignon, 2014). The effectiveness of treatment is also sometimes assessed by measuring changes in attitudes towards the use of substances (Mignon, 2016). The findings from systematic reviews are useful in providing a detailed overview of the availability of evidence on a topic, identification of gaps in research and identification of methodological flaws which could enhance further research in the area (Pericic and Tanveer, 2019).

### ***3.8.1 Efficacy of methadone***

Mattick et al. (2009) systematically reviewed 11 studies that involved RCTs to evaluate the effectiveness of methadone. Studies were eligible for inclusion if they compared methadone treatment (the experimental condition) with a placebo or non-pharmacological approaches such as therapeutic communities, withdrawal or waiting lists (the control condition). Mattick et al. (2009) concluded that methadone maintenance is an effective intervention because it is associated with: a) better rates of treatment retention and b) a greater reduction in use of heroin. However, methadone did not have a statistically superior effect on criminal activity or mortality, in comparison to other approaches. This suggests that methadone is more effective in the achievement of some treatment outcomes such as reduced heroin use and retention but not others. However, the quality of the therapeutic relationship and the intensity of treatment services were noted to have also contributed to the efficacy of methadone (Mattick et al. 2009; Mignon, 2014). It is unknown the extent to which quality of relationships and intensity of services could have contributed to the improved outcomes. More research is needed to determine the facilitators of treatment success, so that its role can be emphasised and developed in the delivery of treatment services, which could in turn improve the wellbeing of the OST population.

### ***3.8.2 Dosage***

Systematic reviews have explored the efficacy of treatment programmes in terms of different doses of substitute medication. The effectiveness of methadone treatment is enhanced at optimum doses of methadone (Mattick et al. 2009). Faggiano et al. (2003) reviewed 21 evaluations including RCTs (11) and Controlled Prospective Studies (CPS;10) to determine the efficacy of methadone at different dosages. In comparison to lower doses, methadone doses from 60mg to 100mg per day were found to be more effective in retaining patients in treatment and in reducing the consumption of heroin and cocaine.

### ***3.8.3 Health outcomes***

Platt et al. (2017) evaluated the impact of needle syringe programmes (NSP) and OST on the transmission of Hepatitis C by reviewing 28 studies. The studies included prospective, retrospective cohort studies, case-controlled studies and RCTs. The use of OST was found to reduce the risk of transmission of Hepatitis C by 50%. The combination of NSP and OST

reduced the risk of transmission of Hepatitis C by 74%. However, Platt et al. (2017) cautioned that the evidence was only of low to medium quality because none of the studies used RCTs, which reduces the overall completeness and applicability of evidence. (Platt et al. 2017). Furthermore, Platt et al's (2017) study suggested that the benefits of OST on transmission of Hepatitis C may be dependent on the sex of the individual. For instance, Platt et al's (2017) found that the benefits of OST on transmission of Hepatitis C may be reduced for females. None of the studies considered the underrepresentation of females in OST (Platt et al. 2017). Furthermore, females could be at higher risk of Hepatitis C in comparison to men because of injecting sexual partner, initiation into injection by sexual partner and the use of used needles/syringes (Platt et al. 2017).

#### ***3.8.4 Buprenorphine v methadone***

There has been considerable effort put into comparing the outcomes of different types of OST. This is largely about finding out which works best for whom and what is most cost-effective. Mattick et al. (2014) reviewed 31 RCT trials to compare the efficacy of buprenorphine maintenance, placebo and methadone maintenance in relation to retention in treatment, reduction of illicit drug use, decline in criminal activity and reduction in mortality. While high doses of buprenorphine was found to be more effective than the placebo at reducing illicit heroin use, methadone outperformed buprenorphine in retaining more patients in treatment. The superior effect of methadone on retention was attributed to the slow induction of buprenorphine (Mattick et al. 2014). Secondly, the displacement of heroin (a full agonist) by buprenorphine (a partial agonist) could lead to withdrawal, which could in turn increase the likelihood of unsuccessful treatment exits (Mattick et al. 2014; Hser et al. 2016). Another possibility is that the ease of withdrawal of buprenorphine in comparison to methadone could increase the probability of detoxification and successful exit from treatment (Mattick et al. 2014).

#### ***3.8.5 Buvidal***

During the coronavirus pandemic, the Welsh Government (WG) provided £3.3 million for the swift administration of prolonged release buprenorphine (PRB) for heroin users (WG, 2021). Given Buvidal's very recent emergence as a form of treatment, the evidence base on its effectiveness is limited. This means that, to date, no systematic reviews have included

evaluations of this form of OST. The literature that is beginning to emerge about the effectiveness of Buprenorphine is impressively positive. Parsons et al. (2020), approached 20 individuals to be interviewed (15 individuals agreed to participate and fourteen of these fifteen individuals were interviewed) with an average OST history of seven years, from treatment services in England and Wales to explore treatment outcomes and experiences of prolonged release buprenorphine (PRB). PRB was reported to help reduce stigma in comparison to other forms of substitute medication because participants did not have to explain reasons for absence from work. Buprenorphine was also reported to reduce cravings, and consumption of illicit drugs (Parsons et al. 2020). Further, it was also associated with lower levels of anxiety and helped patients achieve a sense of normality in their lives (Parsons et al. 2020; Melichar et al. 2020). However, these findings are limited in that they are based on the views of only fourteen patients (Parsons et al., 2020). One implication is that those who had positive experiences of PRB could have been more likely to participate in the interviews. If this is true, the representation of those who had unfavourable experiences of PRB may not have been captured in the interviews.

### **3.8.6 Summary**

To summarise, the systematic reviews have shown that OST is beneficial in reducing heroin use and improving retention rates. The recent introduction of PRB has contributed to reduction of stigma and achievement of normality among patients who had previously experienced mental dependency on the medication i.e., the day was no longer occupied by the need to take medication. The research suggests that the efficacy of OST varies by dose. Platt et al. (2017) found that the benefits of OST on reduced transmission of Hepatitis C was reduced for females. However, none of the studies reported sex differences in access to OST, which means that it is difficult to fully understand why males achieve greater benefits from OST in relation to reduced transmission of Hepatitis C (Platt et al. 2017). The improved retention rate with methadone in comparison to buprenorphine, raised the important questions of a) how retention could be improved for other forms of medication and b) how the number of unplanned treatment exits could be reduced.

### **3.9 Accessibility to OST in Wales**

The World Health Organization (WHO, 2009a) and WG (2011) stipulate that OST must be accessible to all individuals that need it, including people in prison. Accessibility of treatment is also important because dependency is related with a strong need and compulsion to use drugs (Klein and Oshowale, 2007). To achieve accessibility, treatment services “should be physically accessible, open at convenient times, have no undue restrictions on accessibility and have the capacity to be expanded to accommodate likely demand” (WHO, 2009a, p.11).

An unannounced inspection found that people in Welsh prisons who used opioids but who were not in treatment in the community, were not offered access to substitute medication on the first night of imprisonment but were only offered medication for symptomatic relief of withdrawal (Her Majesty’s Chief Inspector of Prisons, 2018).

Between 2018-2019, 92.6% of people who wanted treatment for heroin had started treatment within 20 working days from the date of referral (WG, 2019). However, this percentage referred to contact with psychosocial keyworkers and not necessarily access to substitute medication (May et al. 2019). The Healthcare Inspectorate Wales’s (HIW) (2018) review of substance misuse services in Wales found that there was a significant waiting period for substitute medication in Wales. Gwent in Wales had a waiting list of three months (60 people) in 2018 (TDPF, 2018). Between January-March 2020, there were 64 individuals waiting for opiate substitute medication in the drug agency were participants were interviewed (Drug agency, 2020).

Being on a waiting list is associated with increased likelihood of adverse physical drug related harms and persistence in offending (TDPF, 2018). This could in turn place undue pressure both on the health and criminal justice system (TDPF, 2018). May et al.’s (2019) study explored the motivations for non-medical prescription drug use (NMDPU) by interviewing people who used illegal drugs and had a recent history of NMDPU in Wales. The prolonged waiting period for substitute medication was found to be associated with increased likelihood of OST patients buying illicit medication to alleviate withdrawal symptoms (May et al. 2019). This could affect the wellbeing of OST patients for two reasons. This could mean that those who buy medication are not consuming the appropriate dose in accordance with medical guidelines.

HIW (2018) stated that OST patients are required to attend appointments while waiting for the prescription of substitute medication in Wales. This can be a barrier for OST patients with chaotic lifestyles to access treatment services (HIW, 2018). The unavailability of substitute medication in some pharmacies means that some OST patients need to travel long distances for the consumption of medication, particularly in rural areas (HIW, 2018). The cost and unavailability of public transport, especially in rural areas can have a detrimental impact on access to substitute medication (HIW, 2018).

Furthermore, the accessibility of substitute medication is adversely affected by the cohort of OST patients who are banned from community prescribing due to complex issues related with mental health (TDPF, 2018). The statistics and research showed that rapid access to substitute medication is restricted in Wales. This means that the Welsh Government's (2011) policy on 'accessibility of substance misuse treatment for all individuals who need it', is not being followed. This means that people who are dependent on heroin are not getting the treatment that they are entitled to.

### **3.10 Drug-related deaths**

The number of heroin/morphine related deaths in 2019 has fallen from 108 to 73 deaths in Wales (PHW, 2020). Between 2020 to 2021, there was an 20% increase in deaths in treatment in England of people who used opioids (Office for Health Improvement and Disparities, 2021). In the period between 2020-2021, there were 3,726 deaths recorded in treatment in England and 65% of these deaths were among those who used opioids (Office for Health Improvement and Disparities, 2021). Opioids accounted for the greatest proportion of drug poisoning deaths in England and Wales in 2020 (2263), which is 48.2% more than 2010 (Office for National Statistics (ONS), 2021). Statistics have shown that the number of deaths that are among people with a history of treatment are steadily increasing in Wales. In 2014-2015, 37 drug treatment episodes were closed due to death, while in 2018-2019, 65 drug treatment episodes were closed to death (reason for death was not reported; WG, 2019). This increase of almost 50% in deaths in treatment highlights the need for research to maximise efficiency of treatment services.

Furthermore, DRDs are related to deprivation, as individuals who died from drug misuse were 7.8 times more likely to live in 10 per cent of the most deprived areas (PHW, 2018). The

increase in DRDs has been attributed to an ageing population of OST patients with complex mental and physical health issues who are also more susceptible to increased risk of overdose and an increase in the use of other drugs (HM Government, 2017; ONS, 2021). However, the view that DRDs are an inevitable consequence of ageing is dangerous because it presumes that these cannot be prevented (Dennis, 2021). Dennis (2021) argued that DRDs are not an inevitable consequence of ageing but can be attributed to the inflexibility of treatment services. This implied that enhancing the efficacy of treatment services could in turn reduce the incidence of DRDs.

## **Conclusion**

This chapter described the practice of OST within drug treatment services. The evolution of substitute medications in response to changing circumstances, misuse and diversion, highlighted that both the pharmaceutical sector (in their development of new safer forms of treatment) and treatment services must be proactive to meet the needs of the OST population. The discussion on the pharmacological component of OST highlighted that treatment services are faced with the tension of preventing diversion and the need to promote the autonomy of OST patients. The injecting method of PRB has addressed this tension to some extent, through reducing (if not eliminating) the opportunity for diversion. However, the next chapter will discuss how administration of Buprenorphine is related with problematic issues too.

The Department of Health (2017) recommended the adoption of non-punitive approaches. However, it is unclear whether the use of person-centred approaches is compatible with OST which limits the autonomy of the patient. The issue is further complicated by the changing focus of drug treatment philosophies. The Welsh Government stated that harm reduction is at the heart of their substance misuse strategy. However, the definition of treatment exits as an indicator of treatment success is incompatible with principles of harm reduction. Research has suggested that this focus on completion of treatment could be motivated by a desire to reduce costs and ethical concerns of indefinite maintenance on substitute medication. The misinterpretation of the recovery agenda within treatment services is incompatible with the person-centred approach for OST patients, who cannot achieve or do not want abstinence.

The systematic reviews of the efficacy of OST showed that substitute medication is effective in reducing illicit heroin use, maximising retention in treatment and reducing transmission of Hepatitis C. However, it is unknown the extent to which quality of relationships and intensity of services could have contributed to the improved outcomes. Further research is needed to determine the facilitators of treatment success, so that its role can be emphasised and developed in the delivery of treatment services, which could in turn improve the wellbeing of the OST population. The Welsh Government (2011) stipulated that treatment must be accessible to all individuals who need it. However, the prolonged waiting period for substitute medications means that people who are dependent on heroin, are not getting the treatment they are entitled to. Overall, the evidence suggests that OST can and does work for many patients. Nevertheless, there are patients who will die in treatment (from overdose) and there are many who do not achieve the outcomes that they might. This chapter identified that there is a cohort of long-term OST patients in treatment services, with complex needs who are struggling to achieve benefits from treatment. The next chapter focusses attention on what is known about those who have been in treatment for many years to identify the barriers to success.

## **CHAPTER FOUR - Barriers faced by the long-term OST population in achieving benefits from treatment**

### **Introduction**

The previous chapter highlighted that OST can be beneficial in many ways such as reducing offending behaviour and improving physical and mental health. However, not all patients are able to achieve such positive outcomes despite being on OST for considerable periods of time. In recent years, particular concerns have been raised about the treatment outcomes of older OST patients (aged 35 or older), who it is observed “have poor prospects of achieving permanent abstinence” (ACMD, 2019, p.11). Research has shown that older problem drug users exhibit a “unique combination of features” including high levels of physical, psychological and psychiatric comorbidities, which present a challenge to health and care services (ACMD, 2019, p.12). However, it is not only ageing patients who fail to thrive in OST, as research has shown that poor outcomes are also experienced by younger patients (Metrebrian et al. 2015). The aim of this chapter is to examine the research literature to establish what is currently known (and not known) about why some patients (young and old) fail to benefit fully from OST even after lengthy periods of treatment.

Before reviewing the literature, there are several important conceptual issues to consider. In relation to terminology, previous research has referred to those who do not benefit from treatment as ‘hard to treat’ or ‘treatment resistant’ (Metrebrian et al. 2015). As explained in Chapter 1, I believe that these terms are stigmatising as they suggest the patient is wholly responsible for the failure to benefit (i.e. they are resistant to change) and that the treatment itself plays no role in the failure. The term ‘treatment resistance’ is often used in the literature to describe those who do not succeed or benefit from treatment. Being labelled as resistant to treatment is problematic in several respects. Indeed, labelling theory asserts that the label can in itself perpetuate behaviours that are consistent with that label and create “new problems that stem from the reactions of self and others to negative stereotypes that are attached to the deviant label” (Bernburg, 2009, p.187). For these reasons, I will avoid the term ‘treatment resistant’ in this chapter.

In terms of timeframe, long-term treatment was defined in this study as five years or more of engagement in OST. The decision to define ‘long-term’ in this way was based on its successful application in previous research (e.g. Notley et al.’s (2015) qualitative review of barriers to recovery) and following co-production discussions with staff and service users at the drug agency.

When defining treatment success and failure, it is important to note that patients may benefit from treatment in some ways, but not other ways. It is not always clear cut as patients may achieve some positive outcomes yet still not feel that they have fully benefitted from treatment. Furthermore, success to one patient may well be failure in another patient’s eyes. Given this complexity, the chapter will begin with a section that explores the concept of treatment success. Clarity on this is important if barriers to success are going to be identified.

The remainder of the chapter will then move on to examine the barriers that prevent achievement of benefits from OST, as identified in the research literature. For clarity and consistency with the thesis as a whole, these barriers will be presented using Zinberg’s (1984) *drug, set and setting* framework (see Chapter 2 for details). The *drug* barriers section will discuss polydrug use, the anticipated effects of reducing doses of OST and the effects of heroin and OST medication. The *set* barriers section will explore issues relating to mental health, identity, beliefs, attitudes and motives. The *setting* section will examine barriers such as stigma, treatment demands, the treatment environment, therapeutic relationships, limited publicity of success stories, and chaotic drug-using lifestyles. The chapter will end with a discussion on the gaps in knowledge, with regards to what remains unknown about the barriers that prevent achievement of benefits from OST.

#### **4.1 What is success in OST?**

The Welsh Government introduced Treatment Outcome Profile (TOP) in 2009 to assess the impact of substance misuse treatment services on drug and alcohol use, physical and psychological health, offending and social functioning (WG, 2020; Appendix 1, see p.366). This TOPS form is used every three months to assess progress and an exit TOPS is completed at the exit of treatment. The WG (2021) also uses Key Performance Indicators (KPIs) to assess the performance of substance misuse agencies (see Figure 1 below). These KPIs provide an indication (albeit a fairly crude one) of how success in treatment is perceived by Welsh

Government. Of most relevance to treatment ‘success’ are KPIs 3, 4 and 5. KPI 3 looks for substance misuse to be reduced or, at worst, to have remain unchanged by the point of review or exit from treatment. Similarly, KPI 4 looks for patients’ quality of life to have improved or to have remain unchanged at the point of review or exit from treatment. Given that there is no requirement for the patient to have stopped their use completely, these two KPIs appear to be aligned with a policy of harm reduction.

*Fig. 1 Key Performance Indicators (WG, 2021)*

*Performance Indicator 1:*

Increase the number of clients who engage with services between assessment and planned ending of treatment, by reducing the incidences of clients who do not attend (DNA) or respond to follow up contact post assessment date.

*Performance Indicator 2:*

Achieve a waiting time of less than 20 working days between referral and treatment.

*Performance Indicator 3:*

Substance misuse is reduced or unchanged for problematic substances between start and most recent review / exit Treatment Outcomes Profile (TOP)

*Performance Indicator 4:*

Quality of life is improved or unchanged between start and most recent review / exit Treatment Outcomes Profile (TOP)

*Performance Indicator 5:*

Number / Percentage of cases closed (with a treatment date) as treatment completed.

KPI 5, however, refers to case closures and treatment completions among those who are either ‘problematic substance free’ or who have achieved their treatment goals (WG, 2021, p.10). The reference to case closures and completions implies that maintenance on OST for long or indefinite periods is not indicative of success in treatment. On the face of it, this does not align quite so well with a harm reduction philosophy. However, it is possible that the drive for closures and completions is less about a drive for abstinence and more about the need to reduce costs and address the ethical issues of indefinitely supporting patients on OST (Magura and Rosenblum, 2001).

The view that long-term OST is not indicative of success, is not an uncommon one. Indeed, research on public attitudes towards achievement of treatment success in Scotland, showed that a significant proportion of the general population did **not** perceive the use of substitute

medication as evidence of success in treatment (Scottish Government, 2016). However, research has shown that being abstinent on exit from treatment is not necessarily a sign of success. Magura and Rosenblum (2001), for example, reviewed the literature and found high rates of relapse and drug-related deaths in the period after exiting OST. By contrast, research has shown that long-term maintenance on OST can result in many positive outcomes. Skinner et al. (2001), for example, conducted a 12-year follow-up study of patients in methadone maintenance treatment and found evidence of decreased consumption of illicit drugs (Skinner et al. 2011). Similarly, Neale (1998) conducted interviews with methadone patients and found that long-term maintenance was related with cessation of withdrawal symptoms, healthier weight and better quality of sleep.

There is some debate in the literature about whether abstinence from illegal drug use, is an appropriate measure of treatment success. Laudet (2007) interviewed inner city residents with histories of heroin or crack dependence to explore their definitions of success. Similarly, Neale, Nettleton and Pickering (2011) interviewed heroin users to explore their definitions of treatment success. In both studies, significant proportions of participants indicated that success was synonymous with abstinence (Laudet, 2007; Neale et al. 2011). Interestingly, while most participants described wanting to achieve abstinence, many were doubtful of their ability to achieve this goal (Neale et al. 2011). Abstinence might therefore be an inappropriate goal for all patients of drug treatment services (ACMD, 2019). Other more appropriate goals might include improvements in health and wellbeing, improved relationships, engagement in meaningful activities, acquisition of material possessions or even acquiring a ‘normal state’ of being (ACDM, 2019; Drug Scope and Recovery Partnership, 2014; Neale et al., 2011; Vigilant, 2008).

Duke (2012) also argued that British drug policies have focussed on reduction of perpetration of drug offences as an indicator of success. However, people who use drugs and commit crimes do not always have access to community capital such as “housing employment, family, health services, education and training” (Duke, 2012, p.13). This is because this cohort of people who use drugs and commit crimes often face legal, social economic barriers that prevent access to community capital. This absence of community capital means that it is difficult to stop offending that is related to drugs (Duke, 2012). Therefore, in order to achieve success, there

needs to be increased focus on formation of social networks, attainment of qualifications and community advocacy (Duke, 2012). Some studies have also defined success in terms of short periods of abstinence, while others have used longer periods. For instance, some participants in Laudet's (2007) study stated that a specific timeframe such as achievement of abstinence for a month, was essential for the achievement of success. However, Dennis, Foss and Scott's (2007) 8-year follow up study of 1162 people entering treatment showed that five years of abstinence was needed for achievement of success and reduced likelihood of relapse.

Evidently, defining success in treatment is complex and research suggests that it cannot be based merely on whether a patient abstains from use or reduces the harm associated with their use of drugs (Neale et al., 2011). There is no one-size-fits-all measure of treatment success as success to one patient could be failure to another. Similarly, what is considered to be success to a patient may be quite different to how staff define success. Indeed, Trujols et al. (2011) compared OST patients and staff scores using the Patient Global Impression of Improvement Scale and the Clinical Global Assessment Scale and found that patients rated their progress in treatment far more positively than staff. The difference could be explained by the possibility that patients have more in-depth knowledge of their situation before treatment and of their progress, in comparison to the pre-treatment situation (Trujols et al. 2011). Another explanation could be that patients are aware of their limited progress in treatment, but they could overrate their improvement to alleviate cognitive dissonance (Trujols et al. 2011). Finally, another explanation could be that staff members are more cynical about the capabilities of their OST patients. Goals are not often mutually agreed within services (Trujols et al. 2011). This could result in the erroneous assumption by treatment services that the definition of treatment success is the same for both OST patients and staff members (Trujols et al. 2011).

#### **4.2 What is failure in OST?**

Within the literature, failure to succeed in (or benefit from) OST has been measured in various ways, including: continued opiate dependency, perpetration of offences, poor functioning, short periods of abstinence from heroin, lack of social integration, and lack of compliance with treatment programmes (Van den Brink et al. 2003; Metrebian et al.2001; Charles et al. 2015; Haskew et al. 2007; Fareed et al. 2014). Failure to succeed has also been described as misusing illegal drugs and alcohol while being prescribed medication (i.e. using 'on top'), missing

appointments and missing daily pick-up of medication for three consecutive days (Department of Health, 2017). These varying measures of ‘failure’ could mean that the recruitment of participants is based on varying eligibility criteria. The implication of this is that the findings of the studies may not be comparable or generalizable, which makes it difficult for lessons to be learned for the future.

Qualitative research sheds some light on what OST patients and providers consider ‘treatment resistance’ to mean. Focus group discussions with service users of substance misuse agencies have flagged up that issues around ‘trust’ and that sometimes trust issues are mistakenly interpreted as signs of resistance to engage with staff (Neale et al. 2015). Therefore the ‘inability to trust’ could be misconstrued as treatment resistance by treatment agencies.

In summary, patients of drug treatment services have reported that success should not be measured purely in terms of abstinence and desistance of crime but should be extended to include non-drug treatment related factors too such as personal growth, health and wellbeing, formation of social networks and attainment of qualifications. Abstinence over longer periods of times has also been associated with reduced likelihood of relapse, although there is some discrepancy on the specific timeframe that is needed for the achievement of success. Researchers have used varying definitions of treatment success, which is problematic as it limits the generalisability of the findings to the OST population as a whole and can also mean that achievement of treatment successes that are recognised by OST patients as important, are not recognised.

### **4.3 Drug barriers**

Having discussed the meaning of treatment success, this chapter will move on to review what is already known about why some people are unable to succeed and benefit from OST despite being in treatment for considerable periods of time. This first section will focus on the *drug*-related barriers identified in previous research. It will be followed by sections that consider the *set* and *setting*-related barriers respectively. As noted in Chapter 2, *drug* variables can be described as the pharmacological effects of the drug and “pharmacological aspects of the experience” (Zinberg, 1984; Zinberg 1984 as cited in Lau et al. 2015, p.2).

#### **4.3.1 Polydrug use**

Polydrug use has been identified as a *drug*-related barrier in Lamonica, Boeri and Turner's (2021) study on overdose in the heroin using population. Moran, Kennan and Elmusharaf (2018) interviewed Irish methadone maintenance patients with an average period of 7.5 years in OST, to ascertain barriers to progress. Many participants in the study reported using benzodiazepines to improve the effects of heroin, which increased their risk of accidental overdose (Moran et al. 2018). The use of illicit benzodiazepines often resulted in the use of heroin because, benzodiazepines were often purchased from the same dealer (*setting*) that sold heroin (Moran et al. 2018) The financial burden of funding two drugs also increased stress in the OST patients' lives (Moran et al. 2018). Polydrug use hindered progress in treatment because it stimulated greater use of heroin and added significant financial stress, which in turn could lead to further drug use to self-medicate the stress.

#### **4.3.2 The anticipated effects of reducing doses of OST**

The expected or anticipated effects of drugs on the user have been described in previous studies as *drug*-related factors (Gossop, 2013). In line with this, the expected effects of OST medication (which are drugs) can also be considered to be a *drug* factor. Kondoni and Kouimtsidis (2017) interviewed ten OST patients (9 on methadone and 1 on buprenorphine) who had been engaged with OST for more than five years to investigate the barriers that prevented retention in treatment. Following negative treatment experiences in the past, the patients described fearing that reductions in their dose of OST would result in painful withdrawal symptoms and would lead to continued use of illegal drugs, loss of employment and relapse (Kondoni and Kouimtsidis, 2017). These fears appeared entrenched and deeply seated within some long-term OST patients and played an important role in them dropping out of treatment early (Kondoni and Kouimtsidis, 2017).

Relatedly, Notley et al. (2015) found that the unpleasant memories of previous withdrawal experiences were sometimes enhanced (and exaggerated) through distortions in recall over time. Furthermore, discussions between OST patients about the extreme discomfort of withdrawal (a *setting* factor) were found to heighten fears of severe withdrawal symptoms (Notley et al. 2015). In the 1980s, Rosenbaum and Murphy (1984) noted that many detoxifications within treatment services were rapid, severe and involuntary due to disciplinary

procedures or missing appointments (*setting* factors). Observations of these uncomfortable detoxifications appeared to contribute to expectations of undesirable effects of reducing doses of substitute medication (Rosenbaum and Murphy, 1984). These findings suggest that practices within treatment settings could elevate fears of reduction of substitute medication. More recently Schwartz (2014) explained that this ‘invisibility of success[ful]’ examples within treatment services means that staff members are only in contact with OST patients who have relapsed, have entrenched problems or have failed in OST. This strengthens the belief of staff members that OST patients will not recover from their dependency which in turn fails to inspire belief in OST patients that achievement of recovery is possible (Schwartz, 2014).

Notley et al. (2015) investigated the experience of long-term OST through qualitative interviews with OST patients at a rural community drug service in the UK. OST patients were recruited if they had been engaged with OST for a period of five years or more. Notley et al. (2015) also interviewed professionals involved in the treatment of long-term OST patients to gain an alternative perspective on treatment experiences. The research showed that the reduction of substitute medication was related with expectations of loss of employment and important relationships, which hindered progress in treatment by preventing the reduction of substitute medication (Notley et al. 2015). Furthermore, the study found that the achievement of successes such as greater involvement in child-rearing practices, intensified the fear of reduction from substitute medication, because the perceived losses were felt to be higher (Notley, 2013).

Schumacher et al. (1992) measured fear of detoxification in a population of methadone maintenance patients via interview, self-report and psychometric measures. After five years of engagement with methadone maintenance, Schumacher et al. (1992) gathered information on methadone detoxification fear, treatment outcome variables (number of treatment episodes, number of months on methadone, number of successful methadone detoxifications, number of methadone detoxification aborts, number of dose variations and number of blind methadone detoxification attempts i.e. where the OST patient is unaware of reduction of dose of methadone) and drug rehabilitation (abstinence from drugs, stable housing and employment, friends with non-drug using network and engagement in purposeful activities). OST patients with fear of detoxification remained in treatment longer, tried fewer detoxifications from

methadone and completed a lower incidence of successful positive detoxifications, in comparison to OST patients with little or no detoxification fear (Schumacher et al. 1992). However OST patients with high levels of detoxification was associated with greater rehabilitation (Schumacher et al. 1992). This experience of benefits from OST could in turn be related to fear of returning to illicit lifestyle, which could strengthen fear of detoxification (Schumacher et al. 1992). This could be because OST patients with high levels of detoxification fear remained in treatment longer and were therefore gaining more benefits from OST (Schumacher et al. 1992).

Kondoni and Kouimtsidis (2017) recommended that treatment services should discuss the impact of previous traumatic withdrawal experiences on current treatment choices and not waste time coercing long-term OST patients into premature detoxifications (Kondoni and Kouimtsidis, 2017). However, the fear of withdrawal from OST is only a barrier to success if success is defined narrowly as detoxification from OST. In other words, fear of withdrawing from OST is not a barrier to success if success is measured more broadly and includes maintenance on a steady dose of OST. For instance, in Schumacher et al's (1992) study, patients who were maintained on OST with high levels of detoxification fear, met more of the drug rehabilitation criteria such as abstinence from illegal drugs, employment/education, socialisation with peers who only used cannabis or alcohol, and engagement in non-drug related activities. This suggests that the interpretations of barriers are dependent on the definition of success in treatment.

#### ***4.3.3 Effects of heroin and substitute medication***

As noted earlier, the effects of drugs on the user are classed as *drug* factors (Zinberg, 1984). Moran et al's (2018) study showed that many OST patients had been exposed to adverse childhood experiences (ACEs), the effects of which persisted in adulthood. OST patients described struggling to cope with their histories of trauma, which resulted in persistent use of heroin (to help manage their stress levels) while engaged with OST programmes (Moran et al. 2018). Moran et al. (2018) recommended collaborative interventions between psychologists, counsellors, psychiatrists and GPs to target management of stress in adulthood of OST patients.

Notley et al. (2015) found that the use of heroin as a coping mechanism for dealing with stress and trauma hindered progress in OST. Patients described how a reduction of medication resulted in the resurfacing of uncomfortable emotions, which, in the absence of appropriate psychological support, strengthened their dependence on substitute medication (Notley et al. 2015). It was therefore recommended that the provision of psychological support be offered to patients during the process of reduction to enable OST patients to move forward in treatment. Interestingly, in addition to emotional pain, many long-term OST participants reported also experiencing chronic physical pain (Notley et al. 2015). For some patients, OST was perceived as normal medication for alleviation of pain and the fear of physical pain also prevented the reduction of substitute medication (Notley et al. 2015).

De Maeyer et al. (2011) interviewed OST patients who had been engaged with methadone maintenance for a period of five years or more. Some OST patients stated that numbing of emotions was an undesirable effect of methadone, which had an adverse impact on enjoyment and quality of life (De Maeyer et al. 2011). However other participants stated that the effects of methadone were beneficial in blocking uncomfortable emotions (De Maeyer et al. 2011). For some patients, long-term use of methadone created a new physical dependency, which restricted their lives (e.g. the side effects restricted their ability to apply for jobs). But, for other OST patients, methadone opened up doors to employment (De Mayer et al. 2011). These findings illustrate the important point that some factors may be barriers for some OST patients, but the same barriers may be facilitators of success in treatment for other OST patients (De Maeyer et al. 2011). This highlights the importance of adopting an individualised approach to treatment that considers the specific and individual barriers of each OST patient.

#### **4.3.4 Summary**

To summarise, previous research has shown that the *drug* barriers of polydrug use, the anticipated effects of detoxing from OST, and the effects of heroin and/or substitute medication can all prevent patients from achieving benefits from OST. Providing an optimal dose of OST and discussing previous unfavourable treatment experiences were identified as potential solutions that could help to address these barriers and promote progression in treatment. Interestingly, *setting* factors were found to influence the impact of *drug* factors. For instance, the anticipation of the negative effects of withdrawal was found to be influenced by discussions

with peers. Secondly, the use of illicit benzodiazepines increased the likelihood of use of heroin because heroin and benzodiazepines were often purchased from the same dealer. Importantly, the interpretation of what is a barrier to progress is dependent on how success in treatment is understood. For instance, fear of detoxification was related with failure to exit treatment but enhanced likelihood of rehabilitation. Another important point is that barriers are not the same for all OST patients.

#### **4.4 Set barriers**

*Set* is defined as “the attitude of the person at the time of use” (Zinberg, 1984, p.5)., Personality attributes, previous experience of drugs, mood, motives and expectations of the person who uses drugs can also be categorised as *set* (Mui et al. 2014; Jansen, 1997; Lau et al., 2015). Expectations are described as “a person’s expectation of what a drug will do, considered in the context of a whole personality” (Shewan et al. 2000; p.438). This *set* factor of expectation can be differentiated from the *drug* factor of expectations of drug effects, given that *set* expectations of the drugs’ effects are related to the individual’s personality rather than to the effect of the *drug*.

##### **4.4.1 Mental health**

Psychoses, depression and anxiety are classed as *set* because they describe an “emotional state of mind” (Lamonica et al. 2021, p.7). Admittedly, these mental health diagnoses could also be classed as *drug* factors because personality is influential in the effects of drugs experienced by the individual (Otter and Martin, 1996 as cited in Wright, 2013). However, in these circumstances, mental health issues are classed as *set* because research has shown that OST patients have often experienced mental health issues at a young age and that mental health issues can be triggered by traumatic events in adulthood (Moran et al., 2018). This suggests that mental health issues are not caused by drugs, which implies that *set* might be an appropriate category to describe these emotional states.

Moran et al. (2018) found that adverse mental health issues became a barrier in achievement of benefits from OST, largely because health care professionals only addressed dependence and not broader mental health issues. Therefore, the *setting* factor of not treating mental health issues contributed to this barrier to progress (Moran et al. 2018). Furthermore, it was noted that

the chaotic lifestyle of OST patients and subsequent non-attendance at mental health appointments could sometimes result in crisis. Moran et al. (2018) therefore recommended collaborative work between counsellors, psychiatrists and GPs to address the barrier of mental health and empower OST patients to move forward in treatment. Additionally, it was recommended that drug professionals should be trained in identification of mental health issues and mental health professionals should be trained in issues related to drugs and alcohol (Moran et al. 2018).

Similarly, De Maeyer et al. (2011) assessed the current quality of life (QoL), psychological distress and severity of drug problems in a sample of methadone maintenance patients who had been engaged with OST for five years or more, by administration of a series of quantitative measures. De Maeyer et al. (2011) found that the high incidence of psychological problems (*set*) within the sample of OST patients but **not** drug related problems, was related with low QoL. Therefore the incidence of psychological problems becomes a barrier in the achievement of benefits from OST, because OST is mainly focussed on treatment of physical treatment of opioids (*setting*) (DeMayer et al. 2011). De Maeyer et al. (2011) recommended that treatment services should not solely focus on the treatment of physical dependency but should incorporate a holistic approach that offers practical, social and environmental support to OST patients.

#### **4.4.2 Identity**

In line with previous research that has classed personality attributes as a *set* factor, identity is described here as a *set* factor (Mui et al. 2014). For some OST patients, the strong identity of being a drug user has motivated patients to continue using illicit heroin while on OST programmes, through the belief that life without heroin is not possible (Notley et al. 2015). Notley et al.'s (2015) study found that OST patients either have the 'chronically ill identity' or the 'identifying drug user'. The 'identifying drug user' perceived OST as a continuation of their dependency, while the 'chronically ill' OST patient no longer identified with the drug world and the prescription of substitute medication was just one component of OST (Notley et al. 2015). Those with 'chronically ill' identities saw themselves as fully recovered, even though they were still using substitute medication (Notley et al. 2015).

The experience of barriers in achievement of success was dependent on whether the OST patient had a ‘chronically ill’ or ‘identifying drug user’ (Notley et al. 2015). For instance, the detrimental impact of stigma in gaining employment was more pronounced for the ‘chronically ill’ group. As noted previously in relation to De Maeyer et al’s (2011) study, the implication is that treatment services should adopt an individualised approach based on the individual needs of the OST patient (Notley et al. 2015). However, the *setting* barriers of unemployment and lack of housing were *setting* barriers for both groups with ‘chronically ill’ and ‘identifying drug user’ identities (Notley et al. 2015). As a result of unemployment and poor housing OST patients with both ‘chronically ill’ and ‘identifying drug using’ identities had limited access to entertainment. This increased the vulnerability of the influence of others (*setting*) and resulted in loneliness and boredom (*set*), which could in turn increase the likelihood of use of heroin.

#### **4.4.3 Beliefs, attitudes and motives**

*Set* is defined as “the attitude of the person at the time of use” (Zinberg, 1984, p.5). A key strength of substitute medication is that it alleviates distressing withdrawal symptoms (Moran et al. 2018). The alleviation of withdrawal symptoms resulted in inflated levels of confidence and the mistaken belief that opioid use and cravings could be managed without the aid of substitute medication (Moran et al. 2018). However, these beliefs were, in some cases, found to have a destructive impact on relapse prevention initiatives and prevent progress in treatment, largely because patients thought that they had everything under control (Moran et al. 2018).

Furthermore, the OST patient’s confidence in maintaining their abstinence from heroin did not appear proportionate to the actual achievement of success in treatment (Moran et al. 2018). For instance, some OST patients believed that they did not need long-term OST despite having a history of numerous treatment episodes and lapses (Moran et al. 2018). Other OST patients stated that they were ready to stop the use of methadone after one week’s abstinence from heroin, despite not knowing anyone who had stopped their methadone treatment (Moran et al. 2018). The authors concluded therefore that OST patients often had an inadequate understanding of the chronicity of opioid dependency and the strong likelihood of the need for long-term treatment. Moran et al. (2018) attributed this lack of understanding to inadequate provision of information on substitute medication (*a setting factor*). To overcome this barrier of mistaken beliefs, it was recommended that OST patients should be given psychological

education on the chronicity of opioid dependence (Moran et al. 2018). However, it is difficult to determine at a given point if the perceived onset of readiness is due to inflated confidence levels or other factors such as tiredness of lifestyle, maturity etc.

Motives of the person who uses drugs can also be described as *set* (Lau et al. 2015). The reduction of substitute medication that is coerced by other people (rather than personal internal motivations) has been linked to failure to benefit from treatment and relapses (Notley et al. 2015). This implies that treatment services may need to differentiate between external and internal motivating factors, to ensure that benefits are achieved from OST. For one, OST patient, the structured routine of prison (*setting*) contributed to the motivation (*set*) to maintain abstinence from heroin (Moran et al. 2018). Subsequently, this OST patient felt that the routine of a detoxification centre would help her to overcome dependency (Moran et al. 2018).

#### **4.4.4 Summary**

In summary, mental health, identity, beliefs, attitudes and motives to change are *set* factors that have all been found to influence the achievement of benefits from OST. Secondly, OST patients motivated by internal factors appear more likely to achieve treatment success in comparison to those who are motivated by external factors. This suggests that treatment services may need to deliver different interventions to OST patients who are motivated by internal factors.

#### **4.5 Setting barriers**

*Setting* can be described as “the influence of the physical and social setting within which the use occurs” (Zinberg, 1984; p.5). The change in physical *setting* such as leaving treatment or prison release has also been described as *setting* (Lamonica et al. 2021). The social setting has been described as the group of other people present (including broader values and beliefs of others) and social relationships with others (Mui et al. 2014).

##### **4.5.1 Stigma**

HM Government (2017) has identified that there is an increasing population of complex service users on long-term OST programmes in the UK, who are struggling to achieve positive

treatment outcomes. This population is often exposed to the multiple stigmas of being on OST, ageing, drug addiction and taking psychotropic medication (Conner and Rosen, 2008). Link and Phelan (2001) explain that stigma is often triggered by labelling processes. In relation to drug use, the labelling of an individual as a drug ‘addict’ is often associated with negative stereotypes such as offending behaviour (Anstice, Strike and Brand, 2003). Lamonica et al. (2021) assert that the cultural stigmatisation of illegal drug use can be described as a *setting* factor.

In Notley et al.’s (2015) study, long-term OST patients believed that employers anticipated that people with issues of problematic drug use are only capable of certain types of work. Furthermore, stigma was found to have a detrimental impact on the relationship between the doctor and the OST patient. For instance, research has shown that some doctors refuse to prescribe painkillers to OST patients because they do not believe that the pain is genuine (Moran et al. 2018). This could become a subsequent barrier to progress in treatment because the physical issues of the OST patient are not addressed. Secondly, these experiences of stigma with employment and medical care could strengthen social isolation of heroin using individuals from mainstream culture (Grund, 1993). This isolation could result in deeper immersion within the drug-using culture, which could in itself prevent achievement of benefits from OST (Grund, 1993).

However, Gourlay, Ricciardelli and Ridge’s (2005) study, which involved interviews with methadone maintenance patients, showed that the detrimental impact of stigma was dependent on the characteristics of the OST patient. For instance, OST patients were found to be differentiated on the basis of whether they had functional concepts, non-addict, or conflicted concepts (Gourlay et al. 2005). OST patients with non-addict concepts used positive self-concepts to manage stigma, while those with functional concepts used defensive strategies to cope with stigma. Stigma was found to damage the self-concept of individuals with conflicted concepts (Gourlay et al. 2005). OST patients with conflicted concepts perceived methadone maintenance as a dependency and as a stigmatising treatment (Gourlay et al. 2005). The detrimental impact of the *setting* factor of stigma was therefore dependent on the *set* factor of identity, which in turn was reliant on *setting* factors such as positive relationships. Gourlay et al. (2005) concluded that treatment services must adopt an individualised approach that strived

to meet the varying needs of different users. Treatment services should increase access to resources and provide opportunities for personal development, that could facilitate the development of ‘non-addict’ or ‘functional’ self-concepts, which could in turn strengthen the belief of patients that OST is a beneficial treatment and minimise the impact of stigma (Gourlay et al. 2005).

#### **4.5.2 Treatment-related stigma**

Physical setting is described as “the place, people and things *present* during the time of use” (Mui et al. 2014, p.238; Lamonica et al. 2021). Research has shown that the consumption of substitute medication (a stigmatised act) in a pharmacy setting with non-stigmatised individuals, can make the ‘addict’ identity (a *set* factor) visible to the public (Harris and McElarth, 2012). This enforced visibility of the addict identity has been found to evoke uncomfortable emotions among OST patients that are linked to concerns about risks of confidentiality and embarrassment about drinking methadone in public (Anstice et al. 2003; Harris and McElarth, 2012). Furthermore, OST patients explained that they did not complain about the lack of privacy in pharmacy settings for fear of losing access to their substitute medication (Harris and McElarth, 2012). This power imbalance created by stigma, has resulted in the problem persisting as the issue has been left unaddressed (Anstice et al., 2003). However, the change in pharmacies and engagement with a more helpful and understanding pharmacist has been found to reduce the impact of stigma, enhance self-esteem and initiate recovery (Harris and McElarth, 2012). The administration of Buvidal (prolonged release buprenorphine) has also been found to address the barrier of stigma that is associated with treatment services. Buvidal is a prolonged release formulation of buprenorphine that is administered subcutaneously on a monthly basis (Addiction Professionals, 2020). Hard (2021) presented the case studies of three OST patients in Wales who were administered Buvidal. One of the individuals in the study was a 43-year-old man with prolonged history of drug use, chaotic risk-taking behaviour and previous attempts at suicide. Administration of Buvidal was related with elimination of the barrier of stigma that was related with observation of consumption of methadone (Hard, 2021). Similarly, Parson et al’s (2020) study identified that the monthly administration of Buvidal was related with reduced stigma, because OST patients no longer needed to explain their absence at work.

Stigma has also been found to have a detrimental impact on access to other support services. For instance, Vigilant's (2004) interviews with methadone maintenance patients showed that Narcotics Anonymous (NA) groups often viewed OST with contempt (i.e. the use of substitute medication was not viewed as 'clean'). This stigmatising attitude means that OST patients are sometimes unable to benefit from the daily and intensive support of NA (Vigilant, 2004). To cope with this stigma, some OST patients have reported attending NA sessions without disclosing their use of substitute medication (Vigilant, 2004). However, the efficacy of NA sessions is likely to have been affected because OST patients were unable to fully share their recovery stories with the group (Vigilant, 2004).

Strike and Rufo (2010) interviewed OST patients and staff members at a Canadian treatment centre to explore the perspectives surrounding the process of urine testing in methadone maintenance. OST patients and staff members stated that the process of urine testing strengthened the negative drug-using identity that people who use drugs are untrustworthy (Strike and Rufo, 2010). This reinforcement was identified as a barrier because many OST patients entered treatment in anticipation of the transformation of the non-drug using identity (Strike and Rufo, 2010). The shame of urine testing was also found to result in premature detoxification of substitute medication and termination of treatment in some circumstances (Vigilant, 2004; Dennis, 2021).

#### ***4.5.3 Demands of drug treatment***

Research has shown that the inflexibility of opening times of dispensary settings can have a detrimental impact on the lives of OST patients. For example, the restricted opening hours can interfere with the employment commitments of some OST patients (Anstice et al. 2003). This can mean that OST patients are faced with the difficult dilemma of attending work or the pharmacy. Choosing work over the pharmacy increases the likelihood of missing methadone doses, which can result in the use of illicit substitute medication or heroin to cope with withdrawal symptoms (Anstice et al. 2003). This use of illicit drugs also increases the risk of blood borne transmissions and affects the wellbeing of the OST patient (Anstice et al. 2003). However, the alternative perspective is that the rigid rules and inflexibility of OST, helps to prepare patients for abstinence and societal integration (Vigilant, 2004). Hard's (2021) case studies of OST patients showed that the monthly administration of Buvidal was related with

minimal interference with life. Similarly, in Parson et al's (2020) study, OST patients stated that the monthly administration of Buprenorphine meant that there was minimal interference with employment and the personal life of OST patients.

#### ***4.5.4 Proximity to drug users***

Studies have shown that the OST dispensing setting often facilitates contact with drug-using peers and people selling drugs (Anstice et al. 2003). This contact has been described in previous studies as part of the social *setting* (Mui et al. 2014). Contact with these peers on a regular basis has been identified as a barrier to progress because it facilitates the continual use of heroin (Anstice et al. 2003). The proximity of the needle exchange to the dispensary has also been identified as a barrier to some OST patients, because it means that the OST patient is confronted with people who are continuing to inject drugs (Anstice et al. 2003). The solution of distancing is not possible because OST patients come into contact with drug using peers every time they pick up their script. The desire to maintain secrecy about the stigmatising act of heroin use was a barrier to the development of new friendships (Notley, 2013). This could in turn result in the formation of dependent relationships with other OST patients and staff members, which could lower motivation levels to exit treatment services (Notley, 2013). However, research has shown that the development of non-drug using social networks is important in the achievement of freedom from dependency.

Best et al. (2015) compared a group of individuals who deemed themselves in recovery from alcohol and drugs with a group of individuals who were in drug and alcohol treatment services. The formerly dependent group was characterised by a social network that consisted of more people in recovery, and less people using drugs. They had a better quality of life, had less incidences of depression and anxiety and increased levels of both personal and social capital. Best et al. (2015) concluded that these positive recovery network might be incompatible with the current structure of treatment services. This raised the important question of how treatment services could help OST patients develop positive social networks, enhance recovery capital and achieve success in treatment.

#### ***4.5.6 The therapeutic relationship***

Another *setting*-related factor is the therapeutic relationship. At the commencement of treatment, staff members often perceive OST patients as having impaired psychological functioning (i.e., physical and mental health issues), while OST patients identify themselves as members of a “disadvantaged subculture” (Notley, 2013, p.8). However, with time, OST patients begin to adopt identities that match the views of staff members (Notley, 2013). One implication could be that OST patients believe that abstinence is no longer possible and start to accept that they are psychologically impaired with the need for long-term maintenance (Notley, 2013). Treatment services are therefore faced with the difficult task of differentiating between OST patients who are capable of achieving abstinence from substitute medication and OST patients who need to be maintained. This differentiation and individualised approach is essential to ensure that the intervention matches the specific needs of the OST patient.

Research has identified mixed perspectives on whether the practice of urine testing in OST is a barrier or facilitator of the therapeutic relationship between the OST patient and staff members. Some staff members believe that the practice of urine testing could be beneficial in the identification of potential barriers that could threaten recovery (Strike and Rufo, 2010). For instance, the discovery of tampering of urine samples by one OST patient resulted in the identification of important issues such as domestic violence and inappropriate housing, that could then be subsequently addressed by treatment services (Strike and Rufo, 2010). However, other staff members believe that the process of urine testing is detrimental to the development of trust within the therapeutic relationship, as OST patients should feel comfortable to disclose their use of heroin within a safe environment (Strike and Rufo, 2010). This raised the important question of the reason why some OST patients continue to use OST when they are engaged with OST.

Heikman, Muhonen and Ojanpera’s (2017) study showed that patients with insufficient doses of substitute medication were more likely to use illicit drugs when engaged with OST. This study highlighted the importance of optimal dose of substitute medication (*setting*) to resolve the barrier of polydrug use (Heikman et al. 2017). Furthermore, the inappropriate response of treatment services to drug use (*setting*), could further prevent achievement of benefits from OST. For instance, Dennis’s (2021) interviews with OST patients showed that the imposition

of negative consequences by treatment programmes in response to positive drug test results could lead to dishonesty of OST patients (Dennis, 2021). One implication of the use of punitive measures is that the 'use of heroin' is not discussed within the therapeutic relationship, because discussions could result in greater restrictions including supervised consumption or frequent drug tests (Dennis, 2021). This could mean that important issues are not addressed, which could impede progression in treatment.

To resolve this barrier of the use of punitive approaches and associated non-disclosure of use of heroin, some research has suggested that treatment services should reward negative drug tests that are given by OST patients. For instance, Dallery et al. (2001) explored the impact of voucher-based reinforcement in a population of methadone maintenance patients, who used heroin or cocaine on a regular basis. Participants were assigned to one of two conditions i.e., participants could earn either \$374 or \$3,369 in vouchers for provision of opiate and cocaine negative urine samples (Dallery et al. 2001). In the second phase, the dose of methadone was increased for all participants. The high voucher condition was related with increased levels of abstinence from both cocaine and heroin, in comparison to the low voucher condition. Furthermore, higher doses increased the efficiency of voucher reinforcement (Dallery et al. 2001). Dallery et al. (2001) recommended that the response requirement (*setting*) should be lower for individuals with long terms of heroin use. For example, the provisions of vouchers could be contingent on the use of lower quantities of drugs or abstinence from one drug, as opposed to all drugs (Dallery et al. 2001). Similarly at the initial stages of treatment, shorter periods of abstinence could be required for the provision of vouchers. At the latter stages of the treatment journey, longer periods of abstinence could be required (Dallery et al. 2001). This suggested that the provision of rewards, as opposed to the use of punitive approaches could promote progression in treatment.

Research has shown that the use of heroin could result in termination of treatment or implementation of punitive measures (Dennis, 2021). Furthermore, the risk of overdose is highest at the termination of treatment episodes and on release from prison (due to reduced tolerance), and there have been calls for more research to identify better ways of engaging OST patients on a continuous phase or for planning safe exits from services (Prenoxad Injection, 2019). A prospective study of methadone maintenance patients over the year after treatment

entry showed that repeated detoxifications could increase the tolerance levels of methadone (Trafton, Minkel and Humphreys, 2006). This means that those with a history of multiple treatment episodes will need more and more methadone to eventually achieve abstinence from heroin (Trafton et al. 2006). This could make it more difficult to successfully detox from methadone. For this cohort of OST patients with multiple treatment episodes, increased tolerance to methadone and/or are struggling to achieve benefits from OST, the prescription of heroin could be an appropriate treatment option.

Van den Brink et al. (2003) administered either inhalable methadone, inhalable methadone and heroin, injectable heroin or injectable heroin and methadone to methadone maintenance patients who were deemed to be not benefiting from treatment. All groups received psychosocial interventions (Van den Brink et al. 2003). To be eligible, participants had to have persisted in the use of illicit heroin, have poor physical functioning, poor mental health and limited social integration (Van den Brink et al. 2003). The co-prescription of heroin was related with improvement in physical, mental and social functioning (Van den Brink et al. 2003). This finding appeared to be promising but it must be considered in the context that there was at least one death related to the co-prescription of heroin. Furthermore, 45% to 88% of participants failed to respond to the co-prescription of heroin. Van den Brink et al. (2003) concluded that for some OST patients, other interventions may be needed to optimise the achievement of benefits from OST. The finding must also be considered in the context that the co-prescription of heroin occurred in new settings with new members of staff. Therefore, it is unclear if the findings could be attributed to the co-prescription of heroin or the new therapeutic relationship. For instance, expectations of staff members could have a powerful impact on the achievement of success in treatment (Notley, 2013). However, termination of prescription of heroin resulted in deterioration of wellbeing in 82% of the participants who had been prescribed heroin (Van den Brink et al. 2003). This finding raised the important question of whether long term prescription of heroin is needed for maintenance of achievement of benefits.

Metrebian et al. (2015) also explored the impact of prescribed heroin on the wellbeing of British OST patients who had struggled to achieve full benefits from OST. Metrebian et al. (2015) recruited heroin dependent individuals who persisted in the use of heroin despite engagement with OST. It is important to note that even if someone is abstinent from heroin, they may still

be struggling to achieve the full benefits of OST. These participants were assigned to supervised injectable heroin (SIH), supervised injectable methadone (SIM) and optimised oral methadone (OOM) groups. All three groups received psychosocial and medical support in addition to medication for 26 weeks. Information on illicit drug use, alcohol use, physical health, mental health, social functioning and offending behaviour were gathered at face-to-face interviews. SIH and SIM were found to have no superior effect on wider drug use, offending behaviour, physical and mental health in comparison to OOM. This could be because all three groups received psychosocial and medical support (Metrebian et al. 2015). The absence of a significant effect between the three groups could be, because OST patients may need to be prescribed heroin for a longer time to fully experience the health and social benefits of prescribed heroin (Metrebian et al. 2015). However, SIH and SIM were better than OOM in the reduction of the use of illicit heroin.

Overall, the prescription of heroin is associated with improvements in physical and mental health functioning. However, it is difficult to isolate the impact of prescribed heroin from the influence of other non-drug related factors. The deterioration in benefits following the cessation of prescribed heroin and absence of a superior effect of prescribed heroin after a short period of six months, suggested that long term maintenance of prescribed heroin maybe needed for some OST patients. It is unclear how the high cost of prescribed heron fits in with this need for maintenance.

The cessation of heroin use has also been found to contribute to the development of strong relationships with staff members. These strong relationships are rewarding and have precluded exits from treatment, especially given the limited interactions with the non-drug using environment (Notley, 2013).

#### ***4.5.7 Awareness of success stories***

Female patients at a methadone maintenance programme reported that they were unaware of previous successful detoxifications (*setting*) within treatment services (Rosenbaum and Murphy, 1984). This lack of evidence of success appeared to be a barrier to progress because it contributed to the mindset (*set*) that successful detoxifications are not possible. Rosenbaum

and Murphy (1984) explained that the absence of models of success within treatment services, is because those who have achieved successful detoxifications or recovery have distanced themselves from the drug-using environment to maintain abstinence from methadone. From a research perspective, this distancing of ‘recovered individuals’ from drug agencies could mean that relatively little is known about the factors that contributed to their success. Arguably, since the global financial crisis in 2008 and introduction of austerity measures, there has been a significant rise in volunteers with lived experience in British substance misuse treatment services (Webster, 2021). This increase in the incidence of volunteers could enhance the visibility of success within drug treatment services. For instance, The CFE Research and the University of Sheffield (2021) stated that the employment of people with lived experience can provide positive role modelling and show that the achievement of success in treatment is possible.

#### ***4.5.8 Recovery-orientated discourse***

As discussed in Chapter three, drug treatment services in the United Kingdom have been influenced by the recovery orientated model (Neale, Nettleton and Pickering, 2013). In theory, the recovery model aims to empower users of drugs to reach their potential and actively contribute to society (Neale et al. 2013). Neale et al. (2013) conducted interviews with OST patients to discover whether recovery-orientated treatment resulted in premature detoxification. The research showed that OST patients without extensive treatment histories requested rapid detoxification of substitute medication (Neale et al. 2013). According to Foucauldian theory, this request for rapid detoxification could be evidential of embedding of the recovery agenda within the mindset of some OST patients and the desire to become normal members of society as soon as possible (Neale et al. 2013). However, rapid detoxification was associated with rapid onset of illicit drug use. It was suggested that this was because OST patients had not addressed their underlying issues or failed to learn life skills for coping with abstinence (Neale et al. 2013). Therefore, the interpretation (*set*) that the achievement of ‘recovery’ means exit from treatment, is a barrier to achievement of progress from OST because it contributed to premature detoxification, which in turn resulted in relapse. Notley et al. (2013, p.168) concluded that OST patients had “internalised the recovery agenda “that is prevalent in drug treatment services and policies, which in turn had resulted in premature detoxifications. Notley et al. (2013) cautioned that treatment services must be careful in the way that the recovery model is promoted, in order to prevent premature detoxifications and relapses. Neale et al. (2013) also stated that “the

experiential knowledge of heroin users who have personally attempted recovery is a crucial source of information for both those contemplating their own recovery and those advocating recovery-oriented services” (p.168). Neale et al. (2013) also recommended that treatment services must be careful in the adoption of recovery-oriented treatment because there is a risk of premature detoxification and related adverse outcomes.

#### **4.5.9 Living environment**

In addition to treatment-related barriers, the living and social environment of many OST patients provided limited opportunities for a sense of purpose (Moran et al. 2018). This lack of purpose contributed to boredom and loneliness, which in turn resulted in continual use of heroin (Moran et al. 2018). Moran et al.’s (2018) study showed that homelessness had a detrimental impact on motivational levels to stop the use of heroin when engaged with OST. This is because homelessness precluded the satisfaction of basic needs such as medical care, access to welfare benefits and practical assistance (Moran et al. 2018). The hostel environment also facilitated contact with drug-using peers and people who sold heroin (Moran et al. 2018). This environment of entrenched drug use was a barrier because it often resulted in persistent use of heroin or relapse (Moran et al. 2018). Importantly, the solution of distancing from drug-using peers was described as unfeasible because OST patients commonly lived in shared accommodation with other people who used drugs (Moran et al. 2018). Participants in Moran et al.’s (2018) study stated that they purposefully got arrested to experience the benefits of structure in prison. Unfortunately, this trapped the OST patients in the vicious circle of offending behaviour and prevented them from moving forward and making progress in treatment.

#### **4.5.10 Summary**

To summarise, stigma, interference with life, proximity to drug users, therapeutic relationships, absence of success stories, recovery-orientated discourse and living environment were *setting* barriers that prevented achievement of benefits from OST. One key finding was that stigma within and outside of treatment services and the restrictive nature of OST prevented access to support services, employment and housing. The detrimental impact of stigma was found to affect some OST patients more than others. However, the alternative perspective was that rigid rules could also prepare OST patients for society. The rigidity of OST was observed to become

a barrier when it interfered with opportunities for societal integration such as employment. The recovery orientated treatment and associated discourse was also identified as a barrier to progress because it could result in premature detoxifications and related adverse outcomes. Factors that facilitated contact with the drug using network such as the patient's living environment and treatment settings also increased the likelihood of continual use of heroin while engaged with OST.

#### **4.6 Observations on the evidence base**

Most research on barriers in relation to the long-term OST population has focused on OST patients who are prescribed methadone. There is relatively little research that has focused on the barriers faced by the long-term buprenorphine population. This is of particular relevance given the varying effects of substitute medication and different methods of diversion that are possible with the different forms of OST. One explanation for the absence of research on barriers faced by the long-term buprenorphine population could be that many patients discontinued buprenorphine treatment because it blocks the euphoric effects of opioid use (Evans et al. 2019). The OST patients who continue with long-term treatment of buprenorphine are therefore likely to be abstinent from heroin use and motivated to maintain this abstinence. Given that research has tended to define success in terms of abstinence from heroin, this may help to explain why long-term buprenorphine patients are under-represented in studies investigating barriers to progress. To date, most research has focussed on the exploration of barriers to success faced by the long-term OST population who have been engaged with OST for five years or more on a continuous basis (Notley et al. 2013; Notley et al. 2015; Moran et al. 2018). This means that there is an absence of research on patients who have been engaged with OST on an intermittent basis. This omission is important, because of the increased risk of overdose at the termination of treatment episodes (Prenoxad Injection, 2019).

Geographical bias is also evident within the literature. Indeed, most British research on the barriers faced by the long-term OST population has concentrated on England, with relatively little research on the barriers faced by the long-term OST population in other parts of the UK including Wales. Research on the Welsh long-term OST population is important given the variance in English and Welsh drug policies as explored in the previous chapter. This thesis is also focussed on the improvement of health and wellbeing of the long term OST population in Wales. It is therefore directly relevant to the Wellbeing of Future Generations (Wales) Act

2015 which strives to improve the a) social, cultural and economic wellbeing of Wales and b) achievement of wellbeing goals such as a healthier Wales, a more equal Wales, a Wales of cohesive communities and a prosperous Wales.

Methodological issues in relation to recording practices are also evident. Reisinger et al's (2009) study highlighted the discrepancy in reasons for premature discharge between OST patients and staff members. Approximately 50% of OST patients who were incarcerated were mistakenly categorised as 'Left before completing treatment'. Furthermore, Reisinger et al's (2009) findings were based on information from 'reasons for discharge' forms rather than from interviews with staff members. This finding identified the need for qualitative research to identify potential reasons for discrepancies and to identify ways in which inconsistencies could be channeled towards the improvement of treatment outcomes. This highlighted the need of comparison of perspectives between staff members and OST patients of barriers related to achievement of benefits from OST. Admittedly, Strike and Rufo's (2010) study addressed the topic of urine testing by comparing perspectives of OST patients and staff members. However, there is little research that has aimed to elicit barriers experienced by the long-term OST population through comparison of perspectives between staff members and OST patients in Wales. This discussion on *drug, set and setting* barriers identified that there is a significant proportion of OST patients who are struggling to benefit from OST for a number of reasons.

## **Conclusion**

This chapter began with descriptions of treatment success and introduced the concept of patients 'not benefitting in treatment'. The definitions were found to be complex because of varied interpretations and the finding that treatment success extended to non-drug related factors too. Neglect of non-drug related areas by treatment services and the emphasis on drug-related goals, were found to affect the achievement of treatment success.

The chapter also presented *drug, set and setting* barriers that could prevent achievement of benefits from OST. Polydrug use, anticipation of effects of reduction of substitute medication and effects of heroin and substitute medication were *drug* barriers that prevented achievement of success in treatment. Polydrug use is a barrier because unsafe methods of administration (*drug*) and contact with heroin dealers (*setting*) increased the risks of accidental overdose and

promoted the continual use of heroin respectively. The fear of withdrawal was related to anticipation of undesirable effects of reduction of substitute medication.

Interestingly, the interpretations of barriers to success are dependent on the definition of success in treatment. For instance, fear of detoxification from medication is only a barrier if success is measured in terms of successful detoxification from OST. There were conflicting views on whether the effects of methadone enhanced the quality of life or was a barrier in achievement of benefits from OST. This suggests that the determination of factors as barriers or facilitators of success maybe dependent on the individual OST patient.

Mental health, identity, beliefs, attitudes and motives were *set* barriers found to have affected achievement of benefits from OST. It was highlighted that failure to address mental health issues and non-attendance at appointments by OST patients with dual-diagnosis issues, could mean that mental health issues are not addressed. The strong identity of being a ‘drug user’ was found to contribute to continued illicit heroin consumption, because of the belief that recovery is not possible. The insufficient understanding of the chronicity of opiate dependency and reduction of substitute medication that is motivated by external factors (rather than internal ones) were found to contribute to premature detoxifications of substitute medication and relapses. However, it was recognised that external factors can have a strong impact on the strengthening of intrinsic motivation.

Stigma, the interference of treatment with life, proximity to drug users, lack of visibility of success, certain aspects of the therapeutic relationship, recovery orientated treatment and living environment are *setting* barriers found to have a detrimental impact on achievement of benefits from OST among some patients. Public dispensing practices and urine testing were found to strengthen stigma and subsequently the drug-using identity in some circumstances. Stigma had an adverse impact on accessibility to support, housing and employment opportunities. The monthly administration of Buvidal was found to reduce the barriers of stigma and demands of drug treatment. Contact with drug-using peers and absence of visibility of success contributed to stagnation in OST. However, research has emphasised the important role of the development of non-drug using social networks and increasing the visibility of success, through the

employment of staff with lived experience. The use of punitive approaches in response to positive drug test results could result in reluctance of OST patients to disclose the use of heroin. Conversely, rewarding the provision of negative drug test results could promote progression in treatment. The findings suggested that some treatment services have responded to the use of heroin with repeated detoxification, which could in turn increase tolerance to methadone. Prescription of heroin might be appropriate for OST patients with multiple treatment episodes and who are struggling to achieve benefits from treatment. However, it is unclear if the efficacy of prescribed heroin can be attributed to the medication or other setting factors such as the therapeutic relationship. Internalisation of the recovery agenda could result in premature detoxifications and associated negative outcomes. Furthermore, increased frequency of detoxifications was found to be related with increased tolerance to methadone, increased risk of overdose, and risk of relapse.

This chapter has reviewed the evidence base to establish what is known about why some patients in long-term OST fail to achieve their objectives and succeed in treatment. In so doing, several important gaps in knowledge have emerged. First, there is relatively little research on barriers faced by the long-term buprenorphine and Welsh OST populations. Second, there is little research that has compared the perspectives of staff members and OST patients in elicitation of barriers experienced by the long-term OST population. The inclusion of staff members is important because it allows for the comparison of different perspectives. To date, most research has focussed on the exploration of barriers to success faced by the long-term OST population who have been engaged with OST for five years or more on a continuous basis (Notley et al. 2013; Notley et al. 2015; Moran et al. 2018). This means that there is an absence of research on patients who have been engaged with OST on an intermittent basis. This omission is important, because of the increased risk of overdose at the termination of treatment episodes (Prenoxad Injection, 2019). While most research on barriers in relation to the long-term OST population has focused on OST patients who are prescribed methadone, there is relatively little research that has focused on the barriers faced by the long-term buprenorphine population. This is of particular relevance given the varying effects of substitute medication and different methods of diversion that are possible with the different forms of OST.

One key finding that emerged from the evidence base was that the expertise and knowledge of heroin users who have tried to achieve recovery are invaluable for informing those a) trying to achieve their own personal recovery, and b) OST patients and staff who are working in the field. This thesis therefore aims to elicit the perspectives of the long term OST population and staff members who have direct experience of working with the long term OST population, to inform the development of interventions that could improve the wellbeing of the OST population. The next chapter will explore the methodology used in this project to answer the research question of the barriers faced by the long-term OST population and the solutions which could help to overcome these barriers.

## CHAPTER FIVE - Methodology

### Introduction

This chapter describes the methodology used to explore experiences of long-term opiate substitute treatment (OST) from the perspectives of OST patients and drug treatment professionals in South Wales. There is significant evidence to show that OST is highly beneficial for people who are struggling with their heroin use (World Health Organisation (WHO), 2004; European Monitoring Centre on Drugs and Drug Addiction (EMCCDA, 2021). However, in 2016, researchers based in the Substance Use Research Group in the University of South Wales (USW) and staff working within a drug agency in South Wales recognised the difficulties faced by a cohort of OST patients who are struggling to achieve benefits from OST, despite long term engagement with treatment services (Informal communication Drug agency, 2016). Previous research has referred to this group of people who “appear not to want it nor benefit from it” as ‘hard to treat’ or ‘treatment resistant’ (Metrebian, 2015; Metrebian, 2003).

This project aimed to elicit ‘first person perspectives’ from participants who are involved with OST on a long-term basis. (Wellington and Szczerbinski 2018; p.16). In line with previous research, five years was chosen as a definition of ‘long term’ for the OST population (Notley et al. 2015). The definition of ‘long-term’ treatment was discussed both with individuals with lived experience and Sian Chicken (Director of Drug agency) and it was agreed that ‘five years’ was appropriate to describe the long-term OST population. While Notley et al. (2013) focused on patients who had been engaged continuously for five years, it was agreed that it would be more useful to also include patients who had been engaged intermittently over that period. It was felt that this more inclusive approach would allow for different views on the experience of barriers faced by the long term OST population. Inclusion of people who have been engaged with OST on an intermittent basis is also important because the risk of overdose is high at the termination of treatment episodes (Prenoxad Injection, 2019).

The participant population was categorised into groups, namely: a) the long-term OST population who have engaged with treatment for five years or more on a continuous or intermittent basis, and b) staff members who have direct experience of working with the long-

term OST population. Drug treatment professionals were interviewed too, to provide a different perspective on the topic (Rueda, Brown and Geiger, 2019).

Broadly, the aims of this project were to identify:

a) the barriers that prevent the long-term OST population to achieve treatment success, and

b) ways of improving the health and social wellbeing of the long-term OST population.

In order to achieve these objectives, a qualitative research paradigm was adopted for the “initial exploration of as yet unknown territory” and for “understanding social phenomena” (Wellington and Szczerbinski, 2018; p.16).

The Social Care Institute for Excellence (SCIE; 2013) describe co-production that involves the meeting of minds to reach a solution. Co-production describes the consultations with people who use services and includes working with people who use services on a project that affects them (SCIE, 2013). Co-production is important because vulnerable people have a right to be involved in research that aims to enhance their wellbeing and their involvement could improve the efficacy of interventions (Cairns and Nicholls, 2015). This chapter will explain how I used co-production at various stages of the research project.

I commence this chapter with information on the aims and the research questions this study was set up to answer. This is followed by descriptions of the strategies used to gain access to participants, the different sampling procedures and the different modes of data collection employed. I also discuss how I analysed my data and explore the ethical issues that emerged during the research project. The chapter concludes with a summary of the limitations of the project.

## **5.1 Aims and research questions**

As mentioned earlier, there is a group of opiate substitute treatment (OST) patients who are not benefitting from treatment. The overarching aims of this study are to gain understanding of the barriers faced by the long-term OST population that could prevent achievement of benefits from OST and how these barriers could be addressed by treatment services.

This project seeks to address the following research questions:

- 1) What are the barriers faced by the long-term OST population that prevent them from achieving benefits from this type of treatment?
- 2) How do these barriers prevent the long-term OST population from achieving benefits from OST?
- 3) What are the solutions to overcome the barriers (faced by the long-term population) that prevent achievement of benefits from OST?
- 4) How can treatment services address these barriers to improve the health and wellbeing of the OST patient?

## **5.2 Accessing OST participants and staff members**

In 2017, USW formed a research partnership with two agencies which have a long history of supporting people who experience difficulties with substance misuse (i.e., Kaleidoscope – since 2003 and Barod (formerly Drug Aid) – since 1972). In 2015, both agencies joined with G4S to form a consortium of partners to deliver substance misuse treatment to people living in Newport (45%), Caerphilly (30%), Blaenau Gwent (10%), Torfaen (10%) and Monmouth (5%; Informal communication Drug agency, 2016). The drug agency has 660 prescribing places for voluntary OST patients and 120 spaces for those involved with the criminal justice system (Informal communication Drug agency, 2016). In Newport, opiate substitute medication (OSM) is dispensed from the site of the drug agency. In the remaining four localities, OSM is dispensed from pharmacies (Informal communication Drug agency, 2016). The drug agency also offers harm reduction services such as provision of naloxone, needle exchange, advice on safe injecting and sexual health, blood borne virus testing and vaccination (Drug agency, 2016).

The director of the drug agency at the time of recruitment gave me permission to approach OST patients and staff members for participation in interviews. Using the drug agency as a recruitment pool helped me to recruit appropriate participants because there was a) a significant proportion of long-term OST patients within the drug agency who were struggling to achieve benefits from treatment, and b) a cohort of a diverse range of staff members who had direct experience of working with the long-term OST population. Terry et al. (2017) recommended 30 participants or more for a PhD project that uses thematic analysis to analyse qualitative data. I therefore strove to recruit at least 20 staff members and 40 OST patients. The following section will explore the different strategies used to recruit potential participants.

### ***5.2.1 Recruitment poster***

Initially, I used recruitment posters to recruit members of the long-term OST population. The recruitment posters were displayed at various venues at premises of the drug agency and participants were asked to inform their keyworker if they were interested in participating. This method proved to be highly ineffective as no participants were recruited using this method.

### ***5.2.2 Approaching former clients and liaison with clinical team strategy***

In the initial stages of accessing participants, researchers will aim to recruit participants who will be able to provide data that will help address the research questions (Glaser, 1978). Prior to commencement of the Project, I had worked as an active treatment worker at the drug agency where I planned to recruit participants. In accordance with Glaser's advice (1978), I started potential recruitment of participants at my previous workplace in Torfaen, as I was already acquainted with many of the OST patients and staff members working there. The immense support from staff at the drug agency proved invaluable in accessing participants from the two populations. Interviewing former clients is beneficial because pre-existing knowledge of the clients' experience and life could enrich the data and facilitate open communication (British Association for Counselling and Psychotherapy (BACP), 2019). Evidence of both the above is illustrated by the fact that during my research I had received quite a few requests for follow-up interviews from participants themselves. Moreover, I had felt that I had managed to develop a good rapport with my participants which translated into honest disclosures of what they felt was not working well in their treatment.

It was agreed with the clinical nurse at Torfaen that one way of recruitment could be to coincide potential interview slots with clinical appointments, as participants would be unlikely to attend specifically for an interview due to travel costs. The clinical nurse explained the purpose of the project to potential participants and asked them if they wanted to be interviewed at the clinical appointment. This strategy worked in both Caerphilly and Torfaen as most OST patients agreed to be interviewed in this way.

To minimise the blurring of boundaries between my previous role as a drug worker and my current role as a researcher, the difference between these two was discussed at the beginning of the interview. However, in one interview this issue became pertinent when an interviewee

disclosed content that was evidently emotional to him. I was torn between the role of researcher and my previous role as a drug worker, but I decided to just listen to him, as I felt this was the priority at the given time. At the end of the interview, in accordance with the key ethical principle of avoiding harm to participants, I recommended that he discuss these issues with his key worker. I took this issue to supervision, and it was confirmed that I had taken the right course of action.

Another difficulty I faced in some venues was that many OST patients did not attend their interview slots. One potential participant openly stated that she struggled with appointments and she did not know if she would attend the interview slot but that she would try her best. True to her word, she did not attend the slot but I found her honesty really refreshing. Discussions with staff at Newport highlighted that this recruitment strategy would be ineffective there because clients often missed their scheduled appointments. Staff recommended that I should be present at the base to help with the development of rapport and trust.

### ***5.2.3 Presence at base***

In response to this recommendation, I therefore tried to recruit participants by sitting in the methadone dispensing booth with the clinical keyworker. However, this strategy was ineffective as many OST patients refused to be interviewed or said they were too busy. I initially sensed a feeling of distrust as I was not known at the venue. The clinical keyworker then stated that he had experienced the same when he had started employment and advised me to spend as much time as possible at that location so that I became a familiar face. I also attended informal hot dog mornings with my own supply of other snacks for sharing, to get to know the OST patients as much as possible, and for them to get to know me too.

Instead of approaching OST patients for interviews directly, I initially tried to engage potential participants with informal conversations to build rapport and trust. This strategy proved to be effective as I gradually noticed a change in prospective participants' attitude toward me. For example, OST patients started to initiate conversations, make more eye contact and smile at me. Given my previous experience as a drugs worker, it was important to me that participants

felt valued prior to the interviews. The purpose of these informal conversations was not purely for the process of recruitment, as I felt that both myself and the OST patients benefitted from them. For example, I am of Indian origin and the ethnicity opened up the opportunity to converse with an OST patient, as she was really interested in India. Another example is where I initiated a conversation by talking about Christmas and the weather. This allowed the OST patient to talk more about his children and experience of treatment services. The establishment of rapport before interviews was also found to be helpful at 'The Hub' in Newport, as I felt that the interviews there lasted longer, were more detailed and more relaxed.

However, one disadvantage of this approach was that some participants were happy to engage in casual conversations, but were unwilling to participate in the formal interview. Similar to Kelly (2010), some prolonged conversations with prospective participants revealed the fact that they were not eligible for the interview! For example, in one case I only found out that one of the people I recruited and started interviewing was ineligible after the interview had started (because she had not been in OST for five or more years). At this point, I thought it would be unethical to terminate the interview and allowed her to talk for the hour. After this incident, I asked any OST patients whom I had conversed with and who had consented to participate how many years they had been engaged with OST. This ensured that all participants met the recruitment criteria before the interview.

Another disadvantage was that the crowdedness of the environment also interfered with the interview. One example was that a participant was telling me that crowdedness of the service was a barrier for treatment success because it took away valuable time from staff members to carefully listen to OST patients. As he was expressing this point, there were numerous knocks on the door and we were repeatedly disturbed. This was both powerful and emotional for me, as what the participant was saying was actually being reflected in reality at the interview.

One key point that emerged from the 'presence at base' strategy was the importance of flexibility. Furthermore, I felt that trying innovative methods of recruitment was important, as it would help recruit different kinds of OST patient and provide the research with diverse

perspectives. I also wanted to ensure that as many OST patients as possible are given a voice in the research.

One key example is where I interviewed a client by the desk while he was waiting for his methadone. He said he did not have time to sit down but was happy to be interviewed while standing! The importance of flexibility was also highlighted by the fact that some participants were happy to be interviewed outside the drug service while smoking a cigarette, but not in a formal interview room with a Dictaphone. This resonated well with perspectives from the co-production meeting where it was highlighted that some OST patients might prefer informal interview settings. This helped me to realise that following a strict interview schedule in a formal setting is not always necessary.

Presence at the base was also beneficial in Torfaen, as this reminded keyworkers of my Project. Keyworkers started to approach me with potential participants who would be interested in being interviewed. However, in March 2020, I suspended face to face interviews due to the Corona virus (COVID-19) global pandemic. At this point I had conducted 17 face-to-face interviews with the OST population.

#### **5.2.4 Accessing the long-term OST population during the COVID-19 pandemic**

Corona virus is a virus that can be seen in animals and humans (Department of Health and Social Care (DHSC, 2020). COVID-19 is a new virus that has not previously affected humans and is believed to have originated in Wuhan, China (DHSC, 2020). The UK Government issued guidance that social contact should be avoided unless necessary. In response to this guidance, the School of Humanities and Social Sciences Research Ethics Committee suspended all face-to-face interviews in March 2020.

Similarly, due to the COVID19 pandemic, HMPPS withdrew their permission to interview OST patients involved with IRIS (the criminal justice sector of the drug agency) in March 2020. In August of the same year, HMPPS stipulated that people involved with the criminal justice system (CJS) could be interviewed in exceptional circumstances, but because of time

constraints I decided not to make a second application and therefore this group of participants was not included in this research. This was not thought to be a problem as most OST patients have histories of involvement in the CJS. In November 2020, ethical approval was gained from the ethics committee of the USW in November 2020 to conduct telephone interviews, in light of COVID-19 restrictions. The management team at the drug agency kindly offered me a work phone for interview purposes and I found this to be highly beneficial as I was able to contact participants without withholding my number i.e., the data manager said that clients were more likely to answer the phone with known numbers. I was pleased that I had gained ethical approval but was unsure how potential participants could be approached, given that I could no longer access drug agencies.

One method I used was to email keyworkers for identification of potential participants that would fulfil the recruitment criteria and whom I could call over the phone to conduct the interview. However, this strategy only generated two interviews and therefore I needed to find new recruitment avenues.

Palbase is an internet software that “aids the management of drug prescription and provides case management” (Paloma Systems Ltd, 2021). The data manager extracted a list of long-term OST patients with a history of multiple treatment episodes over a 5-year period or more on a continuous or intermittent basis. OST patients were contacted by myself and asked if they would be happy to participate in an interview and interested participants were given an interview time slot that was convenient for them. This strategy proved to be highly effective as I managed to recruit 17 OST patients via this method. The ‘lockdown’ period could have been a contributory factor to the high participation rate as many OST patients were at home during the interviews and had more time. Only one participant recruited via this method was previously known to me. Similar to my experience with face to face interviews, some participants did not answer the phone when I called them at the time of their interview slot. In these circumstances, I sent them a text asking them to contact me if they wanted to be interviewed. There were mixed responses to their text messages, as some OST patients failed to respond to the text message, while other OST patients replied and said they wanted to rearrange. However there were some OST patients within the latter group who failed to attend the rearranged appointment too.

### **5.2.5 Accessing staff members for interviews during the COVID-19 pandemic**

In April 2020, I discussed the possibility of conducting online interviews with staff members with my supervision team and the Director of the drug agency gave consent for staff members to be interviewed as part of my study. Staff members were included as it was felt that they could give a different perspective on the barriers faced by the long-term OST population. Because I only had ethical approval to interview OST patients, an updated ethics form was submitted to USW's ethical committee (Appendix 8, see p.383). Ethical approval was granted soon after, which meant I was now able to proceed with recruitment of staff members.

Initially, I asked all team leaders (i.e., middle level managers) if an email could be circulated to all staff members explaining the aims of the Project and if they would be willing to be interviewed. Despite the support from team leaders, this strategy was ineffective as I only had minimal response from staff. I therefore decided to write personal emails instead. This personalised strategy proved to be more effective than the group email and using this method I successfully recruited and interviewed 20 staff members who had direct experience of working with the OST population.

### **5.2.6 Sampling procedure**

Bonevski et al. (2014) describe 'hidden populations' as people who may not want to be identified by certain characteristics such as drug use or homosexuality. People who use drugs become visible upon entry to treatment settings (Watters and Biernacki, 1989). However, there could still be an element of invisibility in treatment populations, as OST patients who are struggling in treatment, may spend little time in services due to social anxiety, negative perceptions of treatment services or other difficulties in their lives. As a result these patients may have been less likely to be approached and asked to participate in an interview.

Sampling involves the selection of participants who are directly relevant to the objectives of the research, consideration of issues on what should be examined and how many participants are needed to ensure that the collected data will be useful (Coyne, 1997; Lubrosky and Rubinstein, 1995). Probability sampling is based on a specific randomisation process, while

non-probability sampling is based on the selection of participants that are both “accessible and available” (Maninder, 2016; p.505). Non-probability sampling was chosen because it is a) recommended for qualitative research as it is a discovery-orientated approach, and b) it reduces costs and maximises time resources (Lubrosky and Rubinstein,1995; Boneviski et al. 2014).

Purposive sampling, a type of non-probability sampling, was used to recruit participants (Maninder, 2016). The power of purposive (or purposeful) sampling is defined by the recruitment of participants that have the potential to provide rich information, which can deepen the understanding of the aims of the research (Patton, 1990). Two samples were used in this study, namely a) OST patients previously or currently involved with OST for a period of five years or more on an intermittent or continuous basis, and b) drug treatment professionals who have direct experience of working with the long-term OST population.

One advantage of adopting a diverse sampling approach is that it could result in a sample that reflects the diversity of the human experience (Lubrosky and Rubinstein, 1995; p.11). Initially, I sought to recruit patients who had been in long-term OST who were either ‘benefiting from treatment’ or ‘not benefiting from treatment’ in an attempt to obtain diverse perspectives. In practice, however, I had to recruit patients who had been in long-term OST who were willing to participate. It is possible, therefore, that the views and experiences of this group of willing participants may differ in some way to the views of those who were not willing to take part. Generalisation of the findings must therefore be made with a certain degree of caution.

At the KESS research proposal stage, it was estimated that 40 OST patients and 20 staff members would be needed to provide the required information for the project. It is difficult to specify the exact number of participants at such an early stage for qualitative projects, because the number of participants required to achieve thematic saturation (where further observations and analysis reveal no new themes) often emerges with time (Lubrosky and Rubinstein, 1995). However, it has been argued by some researchers that the uniqueness of each life means it is impossible to achieve data saturation in its purest form (O’Reilly and Parker, 2012).

O'Reilly and Parker (2012) assert that researchers must explicitly state whether they have achieved saturation and also how this was reached. I attempted to achieve thematic saturation through consistent reviews of interview transcripts and regular consultations with my supervision team during the data collection period. In practice, thematic saturation, constraints of the budget and time resources were all used to determine the final number of participants (O'Reilly and Parker, 2012). O'Reilly and Parker (2012) explain that the influence of time and budget factors on the decision to stop recruitment does not invalidate the findings. Similarly in my experience, the budget the project was also an influential factor in determining the number of participants for the project.

Overall, the sampling procedure allowed me to include a diverse range of experiences, but the sample also had a sufficient number of homogenous participants to allow for comparative analyses within the participant populations (Lubrosky and Rubinstein, 1995). Fig. 1 shows that OST patients were dispensed a diverse range of substitute medications (with methadone by far the most common one at more than two thirds of participants), but it also included participants who were waiting for their medication to be prescribed again.

Fig 1 Socio demographic characteristics of OST patients

Number of participants	Sex		Type of OST		Area	
	TOTAL: 38	female	18.4% (n=7)	Waiting lists	5.3% (n=26)	Torfaen
Newport						28.9% (n=11)
Methadone				68.4% (n=26)	Blaenau Gwent	13.2% (n=5)
male		81.6% (n=31)	Buprenorphine	7.9% (n=3)	Caerphilly	21.1% (n=8)
			Buvidal	5.3% (n=2)	Monmouthshire	5.3% (n=2)
			Finished OST	13.2% (n=5)	Unknown	2.6% (n=1)

Notes: \* Some patients were on waiting lists for treatment but had long (5+ year) histories of OST.

As seen in Fig. 2, staff members were also recruited from a diverse range of roles within the clinical and psychosocial interventions teams, and this included doctors, clinical keyworkers, team leaders etc.

Fig.2 Socio demographic characteristics of staff members

Number of participants	Sex		Role		Length of years in experience
	TOTAL: 20	females	55% (n=11)	clinical team	
males		45% (n=9)	psychosocial team	65% (n=13)	

22.5 years average experience (range 1 - 20 years).  
NB: one participant's length of experience is unknown.

### 5.3 Qualitative research and semi-structured interviews

This research is focused on the identification of barriers encountered by the long-term OST population in achieving their goals and on finding ways of improving the wellbeing of the long-term OST population. Social sciences research has differentiated between the quantitative and

qualitative research paradigms (Wellington and Szczerbinski, 2018). Quantitative research is appropriate for projects that aim to predict, explain or control a phenomenon (Wellington and Szczerbinski, 2018). Qualitative research, meanwhile, is appropriate for projects that strive to comprehend participants' subjective experiences, the meanings given to those experiences and the interactions of participants with treatment settings (Fossey et al. 2002).

Given the aims of this project, a qualitative research strategy was adopted. Qualitative research methods have been used frequently in the substance misuse field to explore topics such as overdose, initiation of drug use, the impact of heroin on peer networks and the association between heroin treatment services and drug-related deaths (Ataints et al. 2020; Khozbi et al. 2009; Best, Manning and Strang, 2007; Dennis, 2019). The approach provides a useful way of capturing detailed accounts of memorable experiences that are personal and relevant to participants' lives (such as key barriers to treatment success) (Khozbi et al. 2009). To date, most research that has sought to improve the wellbeing of long-term OST patients has been quantitative in strategy and has involved "correlating characteristics of users with key outcomes", as in Metrebian et al's (2015) study (Informal communication Drug agency, 2016, p.4). It was felt that employing a qualitative strategy would therefore add a new perspective to the existing literature on this topic and help to fill an important gap in knowledge.

With regard to the interviews, while the use of structured interviews can help to reduce researcher bias, elicit more objective data and enhance the generalisability of the findings, this is often at the expense of richness of data and flexibility (Qu and Damay, 2011). Semi-structured interviews were therefore deemed to be more appropriate because of their flexibility and the opportunity that they presented for wider discussion about related issues. I felt this was needed to help develop rapport with participants and to enable me to address personal issues in a sensitive manner (DeJonckcheere and Vaughan, 2019).

### ***5.3.1 Interview schedule***

While trying to build a relationship with staff at the drug agency, I drafted numerous versions of the interview schedule to ensure the elicitation of answers were relevant to the research questions. I used the co-production approach to work with service users at the Hub to develop

a preliminary interview schedule. The final interview schedule consisted of open-ended questions, categorised in seven sections (Appendix 2, see p.367). The first section aimed to gain background information about the interviewee and whether they perceived themselves to be benefitting from treatment or not. The second section explored the initiation of heroin use and previous treatment experience. The third section focused on the interviewee's experience of treatment and their day-to-day life. The fourth section centered on definitions of treatment success and failure, while the fifth section discussed progress towards achievement of goals. The sixth section focused on the most recent treatment experience and was aimed at a) identification of barriers that affected the achievement to treatment success and b) factors that contributed to treatment success. The seventh section focused on identification of ways in which the wellbeing of long-term OST patients could be improved. The final section asked for feedback on the interview and if there was anything else the interviewee would like to add. This last section, which encouraged interviewees' reflexivity, allowed me to gain feedback on how my practice could be improved for future interviews. For example, one participant suggested a break midway through the interview, which is something I later used in the case of longer interviews.

### ***5.3.2 Pilot interview***

After the final interview schedule for OST patients was drafted, I conducted two test interviews with friends. Test interviews are recommended because "they furnish the research with an opportunity to explore language, the clarity of the questions and aspects of active listening" (McGrath, Palmgren and Liljedahl 2019, p.1003). After the first pilot, my friend Ann said the interview allowed her to explore issues in more depth. However, she also stated that based on her previous experience of working with people who use drugs she felt the language of the interview might be inaccessible for this particular population. I followed this advice and in my subsequent test interview with Candice (another friend of mine), I altered the wording of my questions to make them more appropriate for a non-academic audience. Moreover, in this second pilot interview, I only used the interview schedule as a guide and used what the 'interviewee' said as a starting point to elicit answers to the questions. I felt that this latter approach was easier for me to employ as it allowed me (and probably the participants) to feel more comfortable during the interview.

### 5.3.3 Interviews with OST patients

During the initial data collection phase, I interviewed 18 long-term OST patients face to face. However, in March 2020, face-to-face interviews were suspended due to COVID-19 restrictions. In addition to the formal research interviews, informal discussions with members of the long-term OST population were also held. For clarity and to distinguish them from the formal interviews, these informal discussions are referred to as ‘field notes’. The average duration of the thirty-six interviews with the long-term OST population was 58.92 minutes (one interview was deleted by mistake and one participant refused to be recorded). The length of the interview depended on various factors such as whether the participant had friends waiting for him/her outside, another appointment, and their willingness to discuss issues in detail.

Following feedback from the co-production meeting, the initial plan was to interview members of the long-term OST population first and then drug treatment professionals. It was suggested that the interviews with patients could generate topics that could be subsequently explored with staff. However, the pandemic meant that I had to change the temporal order of the interviews and I ended up interviewing staff before I had finished interviewing patients. This turned out to be a positive development as it allowed me to investigate issues identified by patients with staff as well as issues identified by staff with patients. Fig.3 shows the actual temporal order of interviews, number of participants and mode of interview.

*Fig. 3 Temporal order of interviewing participants, number of participants and mode of interview*

<b>Temporal order</b>	<b>Mode of interview</b>	<b>Number of participants</b>	<b>Participant population</b>
First (December 2019-March 2020)	<i>Face to face</i>	18	<i>Long term OST population</i>
Second (June-July 2020)	<i>Online</i>	20	<i>Drug professionals</i>
Third (November 2020-February 2021)	<i>Telephone</i>	20	<i>Long term OST population</i>
		<b>Total-58 participants</b>	

Even though the use of telephone and online interviews was initially dictated by circumstances, I found the experience of phone and online interviews both insightful and very different to face-to-face interviews. These differences will be returned to later in this chapter as well as in the results chapters.

Semi-structured interviews provide coverage of the topics of interest in the research project. They “offer a focused structure for discussion during the interview but should not be followed strictly” (Kallio et al 2016; p.2955). A conversational, open ended and non-directive approach developed by Carl Rogers was used to interview participants, because it avoided bias, allowed the elicitation of private thoughts and discussions of complex processes, and evoked as much information as possible in the interviewee’s own words (Brinkmann, 2013; Khozbi et al. 2009; DiCocco and Bloom, 2006). Active listening skills were also used to elicit in-depth responses from the interviewee (DeJonckheere and Vaughan, 2019).

The adoption of a person-centered approach is important to convey respect, foster self-determination, and elicit authentic responses (Sandvik and McCormack, 2018). This approach resonated with me because it is similar to my previous style of working with clients during my experience as substance misuse worker. However, the development of rapport could mean that the interviewee could give responses that he/she believes are expected by the interviewer (Brinkmann, 2013). To reduce this possibility, I reiterated to interviewees that they could be as open as possible during the interviews. An OST patient commented that my interviewing style was both relaxed and comfortable, which was reassuring for me:

*I think this is a very relaxed way to interview people. I felt comfortable. (P27)*

While conducting an interview, I was aware that I had to achieve a delicate balance between using the questions in the interview schedule and giving freedom to the interviewee to explore spontaneous topics that could be of relevance to the broader research questions. As time progressed, I realised that it was more beneficial to use what the interviewee said as a starting point to elicit answers to the interview questions.

All of the eighteen face-to-face interviews were conducted in venues belonging to the drug agency. Some of the interviews were conducted in private interview rooms, while others were conducted in gyms (operated by the drug agency), clinical rooms or waiting areas. In accordance with advice from the co-production meetings, I took a selection of both biscuits and fruits to the interview to facilitate a relaxed and comfortable setting. It was also nice for me on a personal level to be able to offer participants something for them kindly giving up their time.

I planned to audio record the interviews because the use of an audio digital-recorder allows the interviewer to focus on the interview with minimum distraction (Cook, 2021). However, in some geographical areas, some potential participants were happy to have a conversation but did not want to be interviewed formally, with me using a digital recorder to record the conversation. This could be because the Dictaphone could have had a detrimental impact on the informality of the conversation, or because some people could have been nervous about having their voice recorded (Rutakumwa et al. 2020). In order to reassure participants, I tried to inform them of the purpose of the audio recorder (i.e., just to record data so that I can focus on listening to them), and also explained to them that the conversations were going to be confidential. Only one participant refused to be recorded and in this case, with the participant's permission, hand written notes were made instead.

The first face-to-face interview was conducted in the gym at the Hub in Newport in November 2019. The interview was not pre-planned but a potential volunteer/service user at the Hub stated that he was willing to be interviewed. The rapport I had developed earlier through co-production meetings and regular visits to the Hub, contributed to the participant agreeing to be interviewed. In my research diary, I reflected that the interview was exciting, but the recording device failed to record the interview. I felt an immediate sense of frustration that valuable data had been lost, but I quickly wrote down notes after the interview to prevent problems with recall. Despite this technological setback my supervision team was extremely supportive, which motivated me to proceed with the interviews. Writing notes after the interview can also actually be a form of initial analysis, as the practice allows for the grouping of similar issues (Rutamumwa et al. 2020). Luckily, all the other interviews were successfully recorded, and I

made sure that I always had a back-up device with me to prevent that from happening again! I also made notes of key issues that emerged as interesting, after the interviews.

#### ***5.3.4 Telephone interviews with the long-term OST population***

The COVID-19 restrictions imposed in 2020 meant that I was no longer able to interview participants face to face. I did not include online interviews as a means of data collection for the long-term OST population in my ethical approval application, because the presence of others with the interviewee during online interviews could threaten the confidentiality of the interview. On a practical level, many OST patients did not have access to a computer or internet at home and many did not have experience of the online world.

Social science research has generally assumed that face-to-face interviews is the best form of data collection but in some circumstances the telephone method might be more suitable (Holt, 2010). My initial concern was that I did not want to appear as ‘cold calling’ potential participants, as I did not have the opportunity to meet them beforehand. To address this concern, I called prospective participants to arrange a convenient time in the future for the interview and to give them time to think properly about whether they wanted to take part in the interview or not. The risk of bias could have been reduced in telephone interviews because when I was recruiting participants for face-to-face interviews, I only approached people whom I felt would consent to participate. Contacting potential participants from the database via telephone also reduced the risk of bias from keyworkers because they could have been targeting clients who they thought were more likely to agree to take part in interviews. During these phone interviews, in order to build rapport with my participants I adopted “an open and curious attitude” and stated that I was interested in hearing their perspective because they had direct experience of being involved with treatment. (McGrath, Palmgren and Liljedahl p.1004).

Overall, both the face to face and telephone interviews were rewarding and enjoyable. I felt privileged that the participants were honest and insightful in their responses and experienced a rewarding sense of satisfaction when I saw the development of rapport with time. Telephone interviewees also sent positive texts about the approach of the interview and some of them stated that they were willing to help further in response to the ‘thank you’ text I sent them shortly after the completion of the interview. Below is such an example:

*It was a pleasure talking to you and thank you for listening to me as I do ramble on a bit ha ha ha but that's because you made it comfortable to talk to you, if you need anything in the future too I am willing to help, thank you again (OST patient)*

The absence of non-verbal language in telephone interviews meant that everything had to be expressed verbally by both myself and the participant (Holt, 2010). It has been suggested that this fuller expression could result in the production of richer data (Holt, 2010). Furthermore, my listening skills were sharpened because of the absence of distractions of a busy drug agency. It has been noted that the uncertainty and anxiety of conducting phone interviews can contribute to an element of strangeness within the interview (Holt, 2010). Similar to Holt's experience, I found that this strangeness dissipated as the interview progressed. The use of ice-breaker questions (about the pandemic and weather) and reflective listening skills helped to establish rapport as the interview progressed. Like Holt's (2010) experiences, the responses of the participant became longer and more relaxed after the initial stage of the interview. All telephone interviews were audio recorded with the consent of the participant.

Interestingly, in four of the interviews with the long-term OST population (2 face to face and 2 phone), loved ones of the participants also volunteered to participate in the interview. Because of concerns around confidentiality, I checked privately with the participant if they were happy for these people to be present. All four participants stated that they were happy for their 'loved one' to be present during the interview. The family members were also aware that the sessions were recorded and consented to participate. If I had to make reference to any quotes of loved ones in my analysis of findings, I explicitly specified that the quote was made by the 'loved one' of the OST patient i.e. OST patient's girlfriend.

### ***5.3.5 Sample characteristics of the long-term OST population***

Fig.4 shows the characteristics of the sample of long-term OST patients included in this study. Current or former OST patients were recruited if they had been involved with OST for five years or more on a continuous or intermittent basis. Most of the sample were male and the average age of participants was 44 years, ranging from 29 to 62 years. All sample members had been in treatment for at least five years (either continuously or intermittently) and the average length of treatment ranged from five to 14 years with a mean of nine years.

Fig.4 Sample characteristics of the long-term OST population

Number of participants	Age of the OST population	Average length of treatment
7 females (18%) 31 males (82%)	Average age is 44.1 for 37 participants (two of the participants age was unknown).  Average age of six females was 37.8 (age of one female is unknown)  Average age of thirty males was 46.9 (age of one participant was unknown)  Youngest of the sample was 29 and the oldest was 62	Average length of treatment for 34 participants was 9.4 years (ranging from 5 to 14 years).  Average length of treatment for the five females for which this information was known was 10 years (this was unknown for 2 female participants).  The average length of treatment for the 30 males for which this information was provided was 8.4 years (this was unknown for one male participant).

### 5.3.6 Online interviews with staff members

The inclusion of drug treatment professionals in treatment-related research is important because the perspectives of staff about the aims and duration of treatment are influential in retention of OST patients (Caplehorn, Lumley and Irwig, 1998). Consideration of perspectives of both staff and OST patients is also important to ensure that any differing expectations of treatment success do not have a detrimental impact on the therapeutic relationship (Strike and Rufo, 2010). Semi-structured interviews with drug treatment professionals have been used to explore the issue of diversion in OST (Johnson and Richert, 2014). This method of data collection is useful as it allows for elicitation of richer and more in-depth data than other data collection methods (Alsawwi, 2014). One drug treatment professional stated that the semi-structured approach used by myself encouraged openness and enabled him to add extra information:

*I think the questions were designed to make you think, and it was a conversation as well, so I could sort of go back and add things that I'd forgot, whereas I know if it had been more of a stricter setting, then it may have altered those things, or made me be more closed with my answers. So I think it went quite well." (Staff member)*

Due to the COVID-19 pandemic, and suspension of face-to-face interviews, I conducted online interviews with 20 drug treatment professionals using the Google Meet software. Google Meet is a type of video calling interview platform used by drug professionals in their workplace. “Video calling provides the interviewee with an opportunity not to just talk to their interviewer, but to see them in real time” (Deakin and Wakefield, 2016, p.606). Video call interviews are a valid mode of data collection as they generate reliable and in-depth data equivalent to that of face-to-face interviews, especially in the light of better internet quality in recent years (Lacano, Symonds and Brown, 2016; Deakin and Wakefield, 2016). For confidentiality purposes, only the audio of the interview data was recorded with the consent of the participant. However, I left the video ‘On’ during the conversations so that I could respond to the body language of the participant and also to make the conversation as natural as possible.

Unlike with the patients, there were no absentees and all staff participants attended their required time slot. Eighteen of the twenty participants were previously known to me and this familiarity could have contributed to the 100% attendance rate (Deakin and Wakefield, 2016). The high attendance rate could also be because of the occurrence of interviews during working hours and the passion of staff to improve the wellbeing of long-term OST patients, which was one of the potential benefits of this study. For instance, one participant requested a follow-up interview as she hoped that the findings could be translated into policy.

The interviews with professionals lasted on average 82.35 minutes and all of them were audio recorded. Written consent was obtained for the interviews via email and all participants were aware that interviews were going to be recorded. The interview schedule with drug professionals was similar to the interview schedule with OST patients. The staff interview schedule (Appendix 3, see p.372), however, also focused on the working practices of drug professionals and discussion of factors that could be indicative of either patients struggling with or benefitting from treatment. During the pandemic, questions were also asked about the influence of COVID-19 on treatment practices.

### ***5.3.6 Sample characteristics of drug treatment professionals***

Fig.5 shows a summary of the roles and length of experience of drug treatment professionals who were interviewed. Most of the staff participants were 'generic' key workers (n=14) whose role involved the delivery of psychosocial interventions to OST patients. However, the sample also included a clinical key worker (based in the prescribing team), a clinical team leader, two nurses, GP Specialist in Addictions and GP Principal who has a specialist interest in Substance Use and Learning Disabilities. As a whole, the sample was useful in providing a range of perspectives of people with long and short histories of working in the substance misuse field.

*Fig.5 Role and length of experience of drug professionals*

No.	Current role	Years in the field
1	Keyworker	20
2	GP Specialist in Addictions	15
3	Keyworker	10
4	Keyworker	1
5	Keyworker	12
6	Keyworker	24
7	Lead clinician	15
8	Nurse	7
9	Keyworker	13
10	Keyworker	4
11	Keyworker	10
12	Nurse	9
13	Clinical keyworker	20-30
14	Keyworker	7
15	Keyworker	11
16	Keyworker	15
17	Clinical team leader	8
18	Keyworker	20
19	Keyworker	1
20	Keyworker	?

#### **5.4 ‘Micro ethnography’**

Brewer (2000) emphasises the importance of natural settings and collection of data in his definition of ethnography:

Ethnography is the study of people in naturally occurring settings or ‘field’ by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to

collect data in a systematic manner but without meaning being imposed on them externally (Brewer, 2000, p.10)

Unlike pure ethnography this study did not involve complete immersion into the world of the people I studied. Instead, I observed drug users' actions, conversations and their participation in activities at the drug agency. Wolcott (1980) stated that this type of fieldwork can be described as 'microethnography'. Wolcott (1980) differentiated between 'microethnography' and pure ethnography, on the basis that 'microethnography' focusses on the observation of certain behaviours, as opposed to depiction of the whole cultural system. This definition of 'microethnography' aptly describes my ethnographic research within the project.

The 'microethnography' involved the collection of field notes from my time spent at the Hub and Basement in Newport and the Lighthouse in Pontypool. "The Hub in Newport is a peer-led project for people in recovery – regardless of whether you are or have ever been in treatment. The Hub is driven by volunteers most of whom are in recovery themselves" (GDAS, 2016). The Basement is a busy drug agency situated within the heart of a small city. I regularly visited both the Hub and Basement in Newport to build rapport, attend co-production meetings and informal events such as Hot Dog mornings. The time spent at the Lighthouse in Pontypool involved attending informal cooking sessions and talking to members of staff. Unfortunately, planned fieldwork at the Caerphilly base was suspended due to COVID-19 restrictions. With increasing time spent at the data collection sites, my presence became assimilated within the environment and, with time, OST patients started to greet me, became more relaxed and started to accept my presence (Douglas, 1972).

On my first day in Newport, I sat in the dispensing booth and attempted to recruit participants as they collected their medication. However, only one participant was interested in taking part in my Project. With time, more and more clients started to approach me for informal conversations and discussions about the study I was conducting. This highlighted that 'familiarity' could be an important factor to build rapport for this particular group of clients. As part of the 'microethnography', I found that sitting in the waiting area on my own proved a more effective strategy than sitting with staff members in the dispensing booth for methadone. I am normally a shy person but I quickly remembered from my previous experience as an active

treatment worker that I had to be as proactive as possible and that I had to try and start conversations as often as possible if I was going to make myself noticed and recruit participants for my study.

Visits to the Basement in Newport and informal ‘Hot dog’ mornings during November and December 2019, helped me to build rapport with participants before the interviews. In practice, these visits also provided an opportunity to talk about the research project with potential participants. I also gained invaluable insights on a) barriers faced by the long-term OST population, and b) ways of improving their wellbeing. With the permission of participants who did not agree to be formally interviewed, I made detailed field notes of informal conversations with clients whom I met during these visits and used these in my analysis.

Furthermore, the ‘microethnography’ provided context for what was being said in the interviews. The visits to the Hub gave me the opportunity to witness recovery activities in action and subsequently understand references to ‘recovery activities’ in interviews. I also met many people who had made significant positive changes to their lives, and I found this inspiring because it strengthened my belief that people can make tremendous changes after years of entrenched use of drugs.

## **5.5 Co-production**

The Social Care Institute for Excellence (SCIE, 2013, p.5) described co-production as a process that involves “a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them.” SCIE (2013, p.6) differentiated between participation and co-production and noted that participation involves consultation whereas co-production “means being equal partners and co-creators.” I strongly believe that people who use drugs and treatment services have invaluable expertise given that they have direct experience of many of the issues involved and that they should be included as much as possible in any important decisions that might affect them.

In line with the co-production approach, I set up a co-production meeting to inform my research approach at an early stage of my project. As a result of this meeting, I gained invaluable advice about the definition of key terms such as ‘not benefitting from treatment’ and ‘benefiting from

treatment’. For example, the co-production meeting identified that abstinence from heroin did not always equate to ‘benefitting from treatment’. This insight proved to be invaluable and true, as a significant proportion of the patient sample stated that they were abstinent from heroin but did not feel that they were achieving optimal benefits from treatment. The co-production approach was also used to develop the semi-structured interview schedule. At the co-production meeting, an academic article was taken to help guide the development of the interview schedule. The service users gave really helpful tips such as “*coming across as being relaxed, bubbly open, and with a positive attitude of wanting to learn as opposed to all knowing the answers*”. These tips proved to be invaluable during my data collection phase. The service users suggested that the long-term OST population should be interviewed first, as their responses could inform the development of the staff schedule.

Another piece of advice which emerged from the co-production meeting and proved to be true was that informal venues would be more appropriate for conducting interviews. One volunteer suggested the provision of healthy snacks in addition to biscuits to promote healthy living, given that this may be the only food that many clients ate during the day. In accordance with the advice, I always tried to bring fresh fruit during my visits and interviews. The volunteer stated that offering incentives for participation reduced ownership and participation should be encouraged through other means to help foster a sense of pride. I therefore decided not to offer incentives for participation but offered ‘thank you’ vouchers instead after the interview.

One way of achieving the equality principle of co-production is ensuring that everyone involved gets to know each other (SCIE, 2013). I therefore spent time at the Hub in Newport to get to know both the volunteers and service users, prior to attempting to access participants for recruitment. One key example is illustrated by a particular incident at the Hub, when one volunteer was filling in an application form to become a peer mentor. The volunteer suggested the use of words such as ‘assist’ to describe her work with the research project. It was discussed that the words ‘work with’ might be more appropriate as she had contributed invaluable expertise to the development of the recruitment criteria and the interview schedule. It is hoped that this helped to address the power imbalance between the researcher and participants and also empower her to realise her inner strengths. It is worth mentioning that this volunteer also participated in my interview in the capacity of an ex-OST patient.

SCIE (2013) states that co-production involves reciprocal benefits to the people involved. In line with this approach, 5 personalised ‘Thank you!’ cards and vouchers were sent to people who helped with the development of the project. My initial conversation with Sally (pseudonym name; lead volunteer at the Hub with lived experience of difficulties with drugs) highlighted the need for training opportunities for volunteers. I therefore encouraged her to speak to her new manager and management team about this. Following the ‘planning of the interview schedule meeting’ the volunteers and service users expressed an interest in being involved in the training of staff members, which I subsequently suggested to the training team.

On another occasion, one volunteer highlighted that a potentially confrontational situation had been handled inappropriately by a staff member, whom she did not have the confidence to challenge. We had a discussion about how the volunteer could use assertive communication skills to raise the issue with the staff member. The volunteer said the discussion helped her to think about the issue from a different perspective. The volunteer said that she will try to raise the issue with the staff member in an assertive and polite way. It is worth mentioning that two of the volunteers who contributed to the development of the research project are now in paid employment. Therefore, their involvement in the project may have helped build their profiles and secure employment. In one instance, I helped with the operation of the gym at the Hub. Thank you cards and ASDA gift vouchers were also sent to all staff members who kindly participated in the interviews. This assistance benefited both the treatment service and service users of the Hub as two members of staff and volunteer are required to be present, for the gym to remain open. Overall, the ‘microethnography’ and ‘co-production approach’ proved to be mutually beneficial in many ways.

## **5.6 Analysing the data**

In total, I interviewed 58 participants which included both the long-term OST population (i.e., patients) and drug treatment professionals (i.e., staff). The interviews amounted to 63 hours of audio-recorded conversations. Initially, I transcribed two of the patients’ interviews, but the remaining interviews were transcribed externally given that there were financial resources within the KESS project. The field notes collected during the ‘microethnography’ allowed me to reflect on the research process and identify preliminary answers to the research questions.

I opted to use the reflexive thematic analytic approach to analyse the data. The central feature of reflexive thematic analysis (TA) is that it is based on a purely qualitative paradigm that involves organic coding (Braun, Clarke and Hayfield, 2019). The purpose of TA is to identify patterns of meaning across a dataset that provide an answer to the research questions being addressed. Patterns are identified through a rigorous process of data familiarisation, data coding and theme development (Braun and Clarke, 2019). Reflexive TA assumes that coding of data is a subjective process and that themes are generated by the researcher (Braun et al. 2019). This approach resonated with me because I believe that interpretations are influenced by the values of the researcher (Braun and Clarke, 2006).

Ontology can be described as “views about the nature of the social world and social phenomena (meaning observed facts, events or situations)” (Clark et al. 2021, p.7). Epistemology can be defined as “views about how knowledge should be produced” (Clark et al. 2021, p.7). Braun, Clarke and Hayfield (2019) recommended that the theoretical orientation must be explicitly stated when reflexive thematic analysis is used. To that end, reflexive thematic analysis was used within the critical realist framework. Critical realism assumes that the existence of reality is a) independent of our conscious awareness or knowledge, and b) that the individual experience is mediated by culture, age, ethnicity, class, gender, sexuality and other experiences (Pickens and Braun, 2018). It is stated that critical realism differentiates between ontology and epistemology (Education Studies, 2020). It is epistemologically fallacious to state that people’s views or statements are reality (ontological) when it is one’s knowledge or understanding about reality (Education Studies, 2020). The critical realist approach appealed to me because it resonated with my personal experience of the influence of my pre-existing perceptions on the interpretation of reality. For example, at the onset of this project, I noted in my reflection diary that my own personal belief, knowledge and experience in the strength of motivational interviewing as an intervention could influence my interpretation of findings. This view might be true and meaningful to me but may not reflect the ontological reality. It is also accepted that other factors such as culture, age, ethnicity, class, gender and other experiences may have influenced my interpretation of reality.

The critical realist framework is of relevance to the long-term drug using population given that the experiences of participants are also likely to be influenced by stigma, changing political agendas and socioeconomic status. Discussions within the critical realist framework allowed for the acknowledgement of social injustice and occurrence of social change (Pickens and Braun, 2018). In my methodological approach, I therefore acknowledge that the participants' experiences were true and meaningful to them but they were influenced by factors such as "age, ethnicity, class, gender, sexuality and other individual experiences" (Pickens and Braun, 2018, p.435).

Clarke and Braun (2019) also recommended that the researcher must acknowledge "their personal and social standpoint and positioning" and its potential influence on the research process (Clarke and Braun, 2019; Watanabe 2017). Similar to Watanabe (2017), I was aware that my previous roles as substance misuse keyworker and current role as researcher could influence the answers of interviewees. To minimise this influence, I tried not to express my own views during the interview (Watanabe, 2017). I also conveyed to potential participants that I was interested in their expertise of their involvement in treatment services. After the interviews, many participants stated that I could contact them any time if I needed further help. This helped to confirm that my intention to view participants as 'experts' was successfully conveyed.

To facilitate reflection, I recorded notes in a research diary after every interview. In accordance with Terry et al's (2017) guidance, a two-step process was adopted (i.e., familiarisation with data of each interview and then familiarisation with data across the entire data set). To familiarise myself with the data from each interview, I simultaneously listened to audio files, read the transcripts and made notes during and after the data collection phase. This process allowed me to identify preliminary themes and also generated areas of interest that could be explored further in subsequent interviews.

It is important to note from the outset that the interview schedule was not directly informed by Zinberg's (1984) *drug, set, and setting* framework. Indeed, the decision to use the framework came during the latter stages of the research project after wider reading of relevant research and during the analysis when I realised that the emerging codes and themes were consistent

with Zinberg's framework. The coding of data into these themes was therefore a little less straightforward than it might have been had the interview schedule been ordered around these issues. One implication could be the blurring of boundaries between *drug, set and setting* themes in the analysis of the data.

After reading through hard copies of the interview transcripts and making notes of key themes and issues, the transcripts and notes were uploaded into the qualitative analysis software NVivo 10. Subsequently, a process similar to that used in Ataints et al's (2020) study on overdosing was used to analyse the interview data. Inductive analysis means that coding and theme development is based on "content of data" (Braun and Clarke, 2019). In the first round of coding, codes were generated for each of the following categories: treatment-related barriers, non-treatment-related barriers, treatment-related turning points, non-treatment-related turning points, treatment-related solutions and non-treatment-related solutions. I then recoded the data and grouped codes repeatedly into themes within these six broad categories (Terry et al. 2017). For example, 'busyness of treatment services' was categorised as a treatment-related barrier. Zinberg's (1984) *drug, set and setting* framework was used to re-organise these themes. This categorisation of codes into '*drug, set or setting*' factors was based on a thorough review of the literature. If there was potential overlap between the three factors, the criteria for categorisation of barriers into *drug, set or setting* factors was based on which factor played the most important role as a barrier (Ataints et al. 2020).

After finalisation of the codes on NVIVO, the codes were used to build up themes (Clarke and Braun, 2019). "A theme captures a common, recurring pattern across a dataset, clustered around a central organising concept" (Clarke and Braun, 2019, p.2). One example of a theme in my findings is 'withdrawal'. This theme referred to how the presence of withdrawal symptoms at various stages of treatment could contribute to non-achievement of benefits from OST.

When presenting findings, I did not use quantitative information such as the number of participants who reported a certain viewpoint (Neale, West and Miller, 2014). This is because not all participants were asked questions in exactly the same way and the use of numbers could result in development of "inappropriate generalizations about the findings" (Neale et al. 2014;

p.175). Semi-quantification was used to describe the number of participants with terms such as ‘few’ or ‘many’, to illustrate patterns in data and not to convey generalisability of findings (Neale et al. 2014).

### **5.7 Ethical considerations**

The USW’s Faculty of Business and Society Research Programmes Committee granted ethical approval for this research project in 2017. In 2018-2019, ethical approval was also given by Her Majesty’s Prison and Probation Service (HMPPS) to interview the long-term OST population involved with the criminal justice system on IRIS programmes (the criminal justice component of the drug agency). Due to the COVID-19 restrictions, amendments had to be made to the research project as face-to-face interviews could no longer be conducted. In August 2020, ethical approval was granted from the USW’s Faculty of Life Sciences and Education Research Programmes Committee to proceed with online interviews with staff members.

In March 2020, HMPPS withdrew their ethical approval for all research proposals due to pressures on staff. In August 2020, HMPPS stated that ethical approval would be granted in exceptional circumstances. Due to the time constraints of the Project, I decided not to approach or interview staff members or clients involved with IRIS in the latter phase of the research project. In November 2020, the USW’s’ Faculty of Life Sciences and Education Research Programmes Committee granted ethical approval to resume data collection via telephone interviews with both OST patients and drug treatment professionals.

People who use drugs are recognised as a ‘vulnerable population’ in research (Bell and Salmon, 2011). This vulnerability is attributed to the complexity of whether people who use drugs have the capacity to provide consent and complexities of boundaries of confidentiality (Bell and Salmon, 2011). However, the use of opioids in itself should not be deemed to be indicative of incapacity to consent, because of the diversity of the drug-using population (Anderson and McNair, 2018). The unpredictability of qualitative research also poses risks to the researcher (Punch, 1994).

### ***5.7.1 Informed consent***

The researcher must ensure that informed consent is gained from all participants (British Society of Criminology, 2015). Informed consent means that the researcher must fully explain the research at a level that can be understood by participants, why the research is being undertaken, who is involved in the research and also how the research findings will be disseminated (British Society of Criminology, 2015). To this end, a consent form (Appendix 4, OST patient consent form, see p.375; and Appendix 5, Staff consent form, see p.376) and participant information sheet were provided to all participants (Appendix 6, Information sheet for OST patients, see p.377 and Appendix 7, Information sheet for staff numbers, see p.379).

The consent form explicitly stated my identity as a research student and gave detailed information on the research project. The consent form stated that participation was voluntary and that participants could withdraw from the study at any time. The consent form also stated that the interview would be audio recorded and specified the circumstances in which confidentiality would be broken. In accordance with Aldridge and Charles's (2008) advice, I did not exclude intoxicated participants but only included those who were able to understand the information sheet and articulate clear responses to the interview questions. Participants were also given the opportunity to withdraw from the interview at any time (Aldridge and Charles, 2008).

My previous experience as active treatment worker made me aware of a high incidence of literacy difficulties in the long-term OST population. Therefore, I verbally summarised the content of both the consent form and information sheet to ensure that all participants understood the information as much as possible. Participants were also given the opportunity to ask any questions they may have had about the study. On the advice of staff members, I also strongly emphasised that participation in the study was separate from their OST and part of a research project (i.e., attendance at the interview would not count as attendance at appointments required by the drug agency).

The information sheet outlined details of the project, recruitment criteria and also what would happen to the data they provided to me. The information sheet also gave contact details of people who could be contacted if participants felt distressed or wanted to make a complaint.

Something I had not anticipated at the proposal stage of this project was the contribution or presence of the participants' loved ones or friends during the interview. However, no additional ethical issues emerged as the participant consented (when I asked them privately) to the presence of the loved one at the interview. Retrospectively, I could have gained additional ethical approval to address any specific issues that could have arisen through the presence or contribution of others in the interview.

### ***5.7.2 Confidentiality***

Some participants expressed a preference to be interviewed in informal settings such as the waiting room. I expressed concerns about confidentiality to these participants, but they said they were happy to talk in the waiting room, as they did not have much time. All participants were informed that confidentiality would be broken if there was a perceived risk to themselves or others. I faced two instances where confidentiality had to be broken. In the first incident, a staff member disclosed the potential risks of delivering opiate substitute medication to clients. I discussed the issue with my supervisor and we decided to inform management of the risk, while simultaneously protecting the anonymity of the participant. Management said that I could contact the participant and ask them to contact them to explain their concerns so that appropriate action could be taken. In accordance with this advice, I contacted the participant and invited him to contact management directly with his concerns about delivering medication.

In the second incident, I had phoned an OST patient to ask if she would be interested in participating in the interview. The participant was using heroin and so I gave her harm reduction advice on Prenoxad (a drug that reverses a heroin overdose). She expressed an interest in being interviewed the following week. However, the client did not attend the phone interview but sent me a text saying that she was having suicidal thoughts. I immediately contacted my supervisor and it was agreed that the team leader should be contacted as the client's keyworker was on annual leave. I also sent a text asking how she was and that she

could contact myself or the drug agency if she needed to talk. I contacted the team leader and informed her what had happened. I then followed up with the issue with the team leader and fortunately the team leader had spoken with the client.

### ***5.7.3 Avoiding harm to participants***

The United Nations Office on Drugs and Crime (UNODOC; 2004) states that the researcher must notice verbal and non-verbal cues that could indicate the mood of the interviewee. This is especially important as my interview schedule had potentially sensitive questions. One of the OST patients was very talkative and seemed very comfortable in expressing himself prior to the interview. However, in the formal interview setting, I noticed that he was becoming increasingly restless and he had started fidgeting. Upon noticing these signs, I asked him if he wanted to continue with the interview. He replied that his back was hurting and asked if he could leave. At this point I decided to terminate the interview as it was clear he was not comfortable. I also phoned him after he had left to check if he was ok and informed him that he could speak to his key worker at any time.

In three other interviews, participants became emotional during the interview after disclosure of personally distressing issues. In these circumstances, I used reflective listening skills to listen to the participant and convey empathy. The participants at the end of the interview said they felt better after talking about the issues. I thanked the participants for sharing emotionally sensitive information and signposted participants to their keyworker or relevant support services.

In accordance with advice from volunteers at the Hub, I decided not to offer incentives for participation. The volunteers stated that the motivation to participate should be based on a sense of ownership, willingness and pride. Instead, I sent 'thank you cards' (Appendix 9, see p.388) and ASDA vouchers (volunteers at the Hub had recommended the purchase of ASDA vouchers as this would offer OST patients a wider range of options to purchase goods such as food, clothing etc.) after completion of interviews. I felt distribution of vouchers would reduce the risk of money being spent on drugs which could potentially harm the participants.

Approaching potential participants via the telephone also enabled me to identify their needs and then signpost them to their keyworker. For example, an OST patient said he had received no support for his mental health during the pandemic. I was able to signpost the OST patient to his keyworker and also inform the keyworker of the OST patient's concerns around his mental health (with permission from the OST patient). This incident also highlighted that frequent contact with OST patients can be beneficial in the identification of potential issues that could affect achievement of benefits from treatment. I was also able to signpost another participant to a filmmaking opportunity offered by the drug agency. A drug treatment professional stated the interview allowed him a period of reflection and also to think of ways in which treatment could be further improved. This statement was consistent with Watanabe's (2017) assertion that qualitative interviews can be a source of data as well as an opportunity for interviewees to reflect upon their professional experience.

Some OST patients said they hoped that their responses would help other people who use drugs, as echoed by Fry and Dwyer's (2001) research. Similar to Fry and Dwyer's (2001) research, one OST participant described that the interview allowed him to comprehend his drug use in more depth:

*It was quite cleansing for me to be honest. That's been exorcising my demons and talking about stuff I don't ever talk about to be honest. .. you know. (OST patient)*

#### **5.7.4 Avoiding harm to the researcher**

Sandberg and Copes (2017) state that ethnographic research with people who use drugs is linked with risks of harm to the researcher or legal issues, such as being privy to disclosures of planned crimes. To minimise both these risks, I conducted face-to-face interviews at the drug agency and I used a work phone to maintain professional boundaries between myself and potential participants.

During the research, I heard disclosures of stigma against people who use drugs. Similar to Miller (1986, as cited in Brougham and Uttley, 2017), these disclosures aroused feelings of anger and distress, but these emotions strengthened my motivation to continue with the research project. As mentioned earlier, one potential participant that sent me a text message to

my work phone saying that she was having suicidal thoughts. This incident left me feeling worried and anxious about the safety of the client. It highlighted the vulnerability of the client group and also how easily she had trusted me within such a short space of time. It also made me realise the immense value of the work that drug treatment professionals do on a day-to-day basis.

### ***5.7.6 Ethical issues related with interviewing former clients***

Interviewing former clients is associated with risks of exploitation, power imbalance, dual roles and dependence on the practitioner (BACP, 2019). I attempted to reduce the risk of exploitation and power imbalance by informing all potential interviewees that participation was voluntary and that their decision to take part (or not) would have no impact on their treatment. The risk of dual roles is greatly reduced by the resignation from my role as active treatment worker upon commencement of my PhD (BACP, 2019)

I took the issue of the complexities of ‘interviewing former clients’ to the Action Learning Group at the Women in Academia Programme, prior to the commencement of interviews. “Action Learning is a method for individual and organisational development based upon small groups of colleagues meeting over time to tackle real problems or issues in order to get things done; reflecting and learning with and from their experience and from each other as they attempt to change things” (Action Learning Centre, 2017). I discussed the potential blurring of boundaries involved in interviewing former OST patients both with the Action Learning Group and my supervision team. One issue that did arise was that interviewees asked me if I would be returning to the role of ‘active treatment worker’. However, I used reflective listening skills to reaffirm the difference between therapeutic and research interviews.

## **5.8 Limitations**

Reflection of limitations of research is important to identify potential areas of improvement and also provide context to the reader in which the findings should be interpreted. An important limitation is the opportunistic sampling approach and relatively small number of participants, which means that the findings cannot be generalised to the wider drug-using population (Neale, Allen and Coombs, 2005). However, qualitative research is also advantageous as it can be

perceived as “a means of understanding the lived experiences and meanings of drug users from the perspective of drug users themselves” (EMCCDA, 2000, p.22).

There may also be an element of sampling bias as participants may have been more likely to approach me if they felt that they were benefitting from treatment. This could mean that potentially there could be an underrepresentation of OST patients who do not perceive themselves to be benefitting from treatment (Meyer and Wilson, 2009). Furthermore, the building of rapport prior to interviews could have produced biased samples because those who agreed to participate could have been more engaged with treatment services or the community (Ellard-Gray et al. 2015).

Problems with recall may also affect the reliability of the findings. The accuracy of the responses in the interview could have been adversely affected by a reduced ability to remember emotions and events, particularly with the drug-using population (Neale et al. 2005). However, the interview questions were based on current or recent treatment experiences for many of the long-term OST participants. The participants who had finished treatment a long time ago were still able to reflect on current strategies they used to maintain the positive changes that they had made. My previous acquaintance with some of the participants during my role as active treatment worker and fieldwork at the venues in varying capacities contributed to the development of rapport with the participants, which could have enhanced accuracy of responses (Neale et al. 2005).

Lastly, due to the COVID-19 pandemic I had to suspend interviews with staff members and clients who were involved with IRIS (the criminal justice arm of the drug agency) and fieldwork in other venues of the drug agencies. This could have reduced the representativeness of OST patients who have current involvement with the criminal justice system and affected the recruitment of participants from diverse geographical areas. However, I tried to enhance diversity by approaching long-term OST patients from diverse areas as much as possible via the telephone.

## **Conclusion**

This chapter has described the methodological procedures used in this research project. This chapter started with a background description of the research project and its aims. This was followed by a description of the rationale of the use of a qualitative strategy. The co-production approach and ways of gaining access to participants were described next, followed by a discussion about sampling procedures and the methods of data collection that were utilised in this research. Given the potential vulnerability of the drug-using population, I also considered the ethical implications of conducting this study, including issues around how to minimise harms to both myself and participants.

The chapter concluded with a summary of limitations and how these could impact on the research process and its findings. Overall, the qualitative interviews provided rich data that allowed for the identification of potential barriers faced by the long-term OST population and ways of improving the wellbeing of this group of individuals. As explained earlier, the findings were categorised into *drug*, *set* and *setting* barriers that could prevent achievement of benefits from OST. These findings are presented in a series of three chapters which focus on 1) *drug* barriers, 2) *set* barriers, and 3) *setting* barriers which prevent achievement of benefits from OST. These three chapters will also discuss how these *drugs*, *set* and *setting* barriers could be addressed and resolved to improve the wellbeing of the long-term OST population.

## CHAPTER SIX - *Drug* related barriers

### Introduction

This chapter is the first in a series of three chapters that present the results of the research using Zinberg's (1984) *drug, set and setting* framework. The goal is to draw on the interview data (with staff and OST patients) in order to identify the barriers that could prevent patients from achieving benefits from OST and to group the barriers in a meaningful and useful way. This first results chapter focuses on '*drug*'-related barriers while the second and third focus on '*set*' and '*setting*'-related barriers, respectively.

The main purpose of this first results chapter is to examine the *drug*-related barriers to treatment success and to identify potential solutions to overcome these barriers. According to Zinberg (1984), Richert (2015) and Miu et al. (2014), any factors related to the pharmacological effects of drugs or users' experiences under the influence of drugs could be classed as '*drug*' variables. Participants in this study identified the following *drug* factors as barriers to their treatment success: 1) the existence of withdrawal symptoms from heroin/opiates dependence, 2) the effects of Buprenorphine medication, 3) the motives for using heroin, and 4) the quality of heroin available. In the sections below, each of these are discussed in turn drawing on the interview data to illustrate the points. For clarity, the responses from OST patients (former or current) will be represented as '*P*' (for patient) and the responses from staff interviewees will be denoted as '*S*' (for staff). References to medication in this chapter refer to the use of opiate substitute medication such as methadone, Subutex, Suboxone or Buprenorphine.

### 6.1 Withdrawal symptoms

The first set of *drug*-related barriers to treatment success identified by participants was in relation to the existence of withdrawal symptoms associated with the use of opiates. When heroin is used for a prolonged period and suddenly stopped, unpleasant withdrawal symptoms may occur, which often leads to continued consumption of heroin (US National Library of Medicine, 2019). This withdrawal is classed as a *drug* barrier because it is related to the pharmacological effects of stopping the use of heroin (Zinberg, 1984). The immense physical and psychological pain of withdrawal is powerfully illustrated by the following accounts given by patients during their interviews:

*It makes you sick. You don't sleep, can't eat. You just want to rip your stomach out. Just got no energy. Just can't be arsed to do anything. You just don't give a damn. You're feeling sick all the time. It's horrible. (P29)*

*Aching legs, being sick, sneezing, you're yawning, your eyes are watering, you can't stop moving, you're fidgeting, you've got diarrhoea, you've got stomach cramps, you're up all night. (P22)*

*Because you're so ill, and the craving for that drug is overwhelming. (P6)*

*I would risk five years in prison just to not feel [the pain of withdrawal] for a day. (P22)*

Many participants stated that this withdrawal prevented the achievement of benefits from OST and therefore identified it as a *drug* barrier at varying stages of the treatment process. Evidence of this is provided below.

### **6.1.1 Titration of medication**

The objective of induction onto and stabilisation on substitute medication is to reach the optimal dose of medication as rapidly as possible to alleviate withdrawal symptoms, limit cravings and, ultimately, lead to abstinence or reduction from illicit drug use (Public Health England (PHE), 2021). However, the induction of medication must also be done as safely as possible (PHE, 2021). This is because methadone levels accumulate to toxic levels rapidly during the initial days of treatment (PHE, 2021). Therefore, treatment services need to balance the need of minimisation of withdrawal with the need to avoid sedation or intoxication. This procedure of correction of dose to the effect is termed 'titration' (PHE, 2021). During the initial stage of titration, withdrawal symptoms may occur until the optimal dose of substitute medication is reached (Department of Health, 2003).

A few participants indicated that the titration of opiate substitution medication to the optimal dose was crucial in determining whether an OST patient continues to use heroin or stops using the drug. This happens because often patients are initially prescribed a standard dose of medication (which might not be the appropriate one) and it normally takes some time until the optimal dose is determined and prescribed:

*This (titration) is the most important time I feel. This is where you are either going to make it or you're going to break it. (P14)*

Another OST patient described this period of titration as difficult and painful:

*It's that first forty-eight hours when you first start treatment for heroin; it's horrendous. (P27)*

This titration period was noted to affect the physical wellbeing of the OST patient, because it was perceived to be associated with disturbed sleep patterns and cramps:

*I was having sleepless nights; I couldn't sleep because there was so much of it in my system, but as soon as I was put on sixteen ml I was fine like. (P16)*

*I didn't want to be using as well as having methadone. But the first weekly treatment from what I can remember, it was just the initial cramps and stuff, but that goes on for a week. (P35)*

These unpleasant withdrawal symptoms during titration increased the likelihood of use of heroin among some interviewees:

*When you first start on the methadone it isn't enough to get you to where you need to be for the 24 hours. So, you'll take it and a couple of hours later you'll have to have a bit of gear to get you through to get the next lot of methadone. So, really, you're defeating the object anyhow. (P38)*

*Well he (interviewee's boyfriend) was still bringing little bits of gear, just to top me up while my methadone was being upped. (P21)*

An OST patient stated that the absence of appropriate support from the GP (a *setting* factor) and the lack of willpower to stop using (a *set* factor) during this period further increased the probability of use of heroin:

*You're going to do your grind and you're going to get on with it, or you're going to take your methadone and then you're going to speak to dealers in the night because you can't get through that night, because you can't sleep, because the doctor won't help you. (P14)*

Both quotations (from P21 and P14) suggest that OST patients may be vulnerable to the influence of the social network (a *setting* factor) during the period of titration. The main implication is that OST patients need to be helped from the very start of their treatment episode to resist the influence of negative social networks. Ways in which this might be achieved are discussed below.

Use of heroin during the period of titration could be problematic because it could set the precedent that use of heroin on top of OST medication is normal and necessary to keep withdrawal symptoms at bay:

*The methadone, it's okay for three or four hours, but then you start coming down, feeling... And the more you're taking of heroin before you get the methadone script, the longer... The higher the dosage is going to have to be, and by the time you get up to that dosage you're gonna... because you're still using the heroin, the heroin and the methadone at the same time, you'd be using, you don't want to come off. Do you know what I mean? ...You've got so used to doing it then. It's normal then. You've just got to do it then to feel normal. (P38)*

Interestingly, none of the staff members identified titration of medication as a barrier to achieving benefits from OST. This could be because some staff members find it difficult to fully empathise with the pain of withdrawal because of lack of personal experience:

*I myself have never used any kind of substance, and I wouldn't know what it's like going through withdrawals. I could speak about it, but physically I wouldn't know what it's like. Only the person that's going through it will know what it's like going through withdrawals (S3)*

*I don't think there are many people (staff) here who have actually been on the streets, you know chasing the next hit, so we don't have direct experience of what they're actually going through...I will never know what it's like on a Sunday night, I'm starting to cluck and I can't find ... (S17)*

One implication of this lack of empathy is that the barrier of withdrawal may not be fully addressed by treatment services. This could in turn hinder progression in treatment of OST patients.

Relatedly, one OST patient indicated that it was difficult to convey the pain of withdrawal to non-drug using members of staff with no direct experience with the drug:

*They need to be able to feel the pain and experience the pain, but they can't because you can't give them pain, can you? "Right, we're going to lock you in the corner and not feed you for a week. Then tell me how you feel." (P21)*

## **Solutions**

Support from the OST patient's general health GP (*setting*) for disturbed sleep patterns was described as a useful way of helping with the titration phase and help prevent the use of heroin:

*Because going through the first couple of weeks without thinking about going back on heroin, if you can't sleep when you're coming off... it's not just like not being able to sleep on a normal day. You don't toss and turn. You get leg cramps, bad twitches ... This is the help that needs to come in with the GP. They need to be more... they need to be more savvy about it and need to be more aware and be able to give the help. Everybody knows that's not going to be a long-term thing. It's a short-term thing to get you... just to get you over the first couple of days. (P14)*

An OST patient stated that treatment services must work in conjunction with general health GPs, particularly in the period of titration. Support from the GP at this time could help address sleep problems associated with withdrawal and reduce the likelihood of use of heroin:

*The treatment with the GP should go hand in hand. Some people when they come off heroin and they go on methadone, methadone doesn't cover... like I said earlier, it's not a Band-Aid. It's not a fix all. It doesn't cover everything. You're still going to go to bed and not be able to sleep. You're still going to get twitches and you might get cramps still. (P14)*

The above quote also raised the important issue of whether prescribing doctors at drug agencies have a 'duty of care' to treat non-drug related medical issues, especially if the withdrawal is related to prescription of substitute medication.

The solution of accessing support from GPs for withdrawal during the process of titration is not straightforward as an OST patient explained the stigma of some doctors could mean that the difficult withdrawal symptoms of OST patients are not addressed:

*I think it's just the fact of them (doctors) not having the knowledge, and the fact that they don't want to know, as opposed to... I think it's ... and it's just like... I'm just going to say it, "You're a dirty junkie; I ain't helping you". (P14)*

This suggested that the stigma (*setting*) of some doctors may need to be addressed by treatment services to ensure that withdrawal symptoms during the titration are addressed in an appropriate manner.

Being secure in the knowledge that another dose was available and determination to succeed (*set*) were also seen as effective mechanisms for coping with the difficult titration phase:

*Because I knew, in 24 hours' time I'd be picking up more, so all was well. (P10)*

*You're either going to stay on the programme and stay with it, if you're strong. You're going to do your grind and you're going to get on with it (P14)*

*You've got to fight with yourself not to take any, because you think, "Oh, I could do with some. It wouldn't be a bad idea to get a little bit more, it won't hurt me" but as long as you can say to yourself "No, no, no, no." (P38)*

This suggests that the *set* factor of 'determination' differentiates between those who use heroin during titration and those who do not. This raises the important question of how treatment services could support OST patients who are struggling with the temptation to use heroin.

For OST patients who are struggling to stop their use of heroin during the titration stage, the blocking effects of long-acting injectable buprenorphine (Buvidal) (a *drug* factor) could also initiate readiness to stop the use of heroin:

*The Buvidal helped. More than helped. It like blocked me off it. I just didn't want it. (P38)*

A staff member and OST patients agreed and stated that the prescription of Buvidal helped with the difficulties of the titration phase because of rapid return to normality (and the absence of withdrawal symptoms) following administration of the initial dose:

*so you wake up every morning [after administration of Buvdial] and you feel normal, and you get on with your day. You don't think "where's my tablet; where's my methadone; where's my whatever to get me through the day?" (S2)*

*But I had the [Buvidal] injection, but after that I was feeling a bit normal. Within two hours I was feeling normal. (P38)*

*But I was bad for the first two days [after Buvidal was administered]. But after that, everything was alright then. (P13)*

The difficulties of the titration phase could clearly impede progression in treatment. However, support during this titration phase could help OST patients to move forward in treatment. It is unclear if this provision of support is within the remit of the general health GP or the prescribing doctor at drug agencies. The issue is complicated by the finding that non treatment of issues indirectly related to the use of drugs, prevented the achievement of success in OST.

### **6.1.2 Withdrawal after stabilisation on substitute medication**

It is important to note that even when someone has been titrated to an optimal dose of medication, they may still continue to experience periods of withdrawal. A doctor involved in the prescription of OST, summarised this well:

*So, they're constantly surfing in and out of this mild withdrawal and that stabilisation of their noradrenaline receptors, which is essentially what's driving the withdrawal, is unopposed noradrenaline that's driving back that, then you're suppressing pain with the either prescribed or, acquired illicitly, opiate. (S2)*

For one patient, the fluctuation between withdrawal and stability affected his sleep patterns because he/she was preoccupied with opening times of the chemist:

*SK: Why do you think people use when they're on a script?*

*P: Because you've got to go, pick it up in the mornings, and you're ill in the mornings. I don't sleep. I'm just there watching telly waiting for nine o'clock to come, or half nine, when the chemist opens, you've started clucking. (P29)*

'Surfing' in and out of withdrawal whether at optimal dose or not, is a risk factor for the continued use of heroin 'on top' particularly during the window period between closing and opening times of the chemist. In fact, one patient said that some people were using heroin simply to feel well enough to make it to the chemist to pick up their scripts:

*Some people are taking heroin to get to the chemist. (P29)*

Similarly, another OST patient stated that the time between doses could lead to withdrawal symptoms and trigger a need for heroin to alleviate the pain. This patient described a powerful inner battle between wanting to avoid using heroin but needing heroin in order to alleviate withdrawal:

*but when you get to that point where your methadone will last you overnight until the next lot, until it's time to take the next lot, you've got to fight with yourself not to take any, because you think, "Oh, I could do with some. It wouldn't be a bad idea to get a little bit more, it won't hurt me" but as long as you can say to yourself "No, no, no, no." You're alright. (P38)*

For one patient, the period of withdrawal between doses of medication was associated with low levels of motivation:

*You've got no energy. Just can't be arsed to do anything. Nothing. Can't be arsed to cook. Can't be arsed to do anything. It's hard work. It's like when you've got to go to the chemist for your script, walk all the way down there. You've got no energy. It's bad, it's horrible, and you're clucking in the chemist. (P29)*

## **Solutions**

The fluctuation between withdrawal and stability between doses of substitute medication is clearly a barrier to the achievement of benefits from OST. Several staff members noted that the pharmacological properties of Buvidal could prevent the withdrawal between doses that is typical of other forms of substitute medication:

*So it is, there's no sort of, the dose is dropping down at the end of the day, then you go and get another dose and it comes back up again. The waxing and waning of doses. The constant stream, steady state, you don't have the mood swings and the ups and downs that you get with daily treatment. (S2)*

*All my clients that have turned around and said "I feel great; I feel wonderful," the first thing they say is "I don't feel terrible in the mornings." So the medication doesn't wear off as quickly as methadone or Buprenorphine, or it wears off in a different way. (S13)*

Alternatively, reducing the time between doses and/or providing take-out supplies of other forms of OST (e.g. methadone) were highlighted as ways to alleviate the pain of withdrawal between doses of substitute medication and removing the need for continued use of heroin:

*It was okay when it was weekly, it was okay then, or every two days to pick up. When you're clucking and you've got to go to the chemist in the morning, and you're waiting for it to kick in, when you could just drink it at home, have a cup of coffee and just wait half an hour when it kicks in, you're okay. (P29)*

Traditionally, services have been reluctant to provide take-out supplies of medication for fear of misuse and diversion:

*I mean the best they're ever going to get from us with regards to freedom and methadone treatment is once a week collections; ... We generally as a rule don't do that because of the risks associated of someone taking three weeks' worth of methadone in their hand luggage, or you know they could lose it, or someone could get hold of it. (S13)*

However, when many patients were given take-home supplies of OST during the COVID-19 pandemic, few such problems were noted, which lends support to the idea as a method for improving treatment outcomes:

*We've had to give a vast amount of medication to people who are potentially at risk of overdose, and you know in the circumstances we've had to do this and touch wood, three months in, we've had no concerns. (S13)*

These positive outcomes suggested that treatment services could trust OST patients more with their substitute medication:

*I'm going to advocate for the use of Buvidal definitely, and that we can possibly give people a bit more trust maybe (S13)*

However, the staff member adopted a note of caution because the provision of trust is associated with the risk of the occurrence of detrimental consequences:

*It's difficult to say because you are... it's all well and good trusting people until something goes wrong. (S13)*

Therefore, the provision of trust and flexibility by treatment services could help OST patients to move forward could address the fluctuation between withdrawal and stability. However, treatment services are faced with the potential conflict between provision of trust and management of potential risks.

## **6.2 Effects of Buvidal medication**

The second *drug* related barrier to treatment success noted in the interviews related to the effects of Buvidal. One staff member referred to positive outcomes brought on by the blocking effects of Buvidal (*drug*), which meant that her OST patient could not use heroin anymore. This enforced abstinence, initiated boredom (*set*), which in turn triggered the positive pursuit of hobbies and progression in treatment:

*He didn't like it initially, but he then described himself as finding it... he was bored, because he couldn't take heroin anymore and he'd come to the point in using crack and bit by bit, he took up tie dying and art and then he got housed and he's done amazingly. (S2)*

However, for some patients this clarity of mind brought about by the cessation of heroin use as a result of Buvidal prescription, resulted in the 'flooding' of uncomfortable emotions and triggered the use of heroin again:

*Because, they suddenly have clarity of mind, they can think for themselves, they remember all the bad things they've done, they remember all the bad things other people have done to them and then it really becomes a struggle for them. (S7)*

*You feel as though nothing's going to hurt you, and you're like wrapped up in cotton wool, and as soon as you stop taking it all your emotions come flooding back, and you don't know how to deal with them, so then you end up going back on it because the big wide world is too bad. (P27).*

This suggests that instead of acting as a facilitator to treatment success, the enforced abstinence for some OST patients in the absence of appropriate support could in fact act as a barrier to this desired outcome:

*So, for them [people who are on Buvidal], unfortunately, they tried to use heroin, they can't get any help out of it, they try to use crack, they can't come down on it, so, for them, Buvidal is like enforced torture. (S7)*

*So, for some people, putting them on Buvidal when they're not ready is like asking somebody to climb Mount Everest I suppose and they're not very fit. (S7)*

As explained earlier, the blocker properties of Buvidal increase the likelihood of cessation of heroin use. This can lead to an improved clarity of mind, which in turn can be an optimal period for counselling:

*If you get clean, and then start proper counselling, it would be more beneficial then because it's more raw, and you're more in touch with your feelings then. Definitely, without a doubt. (P6)*

*You just... You feel totally different. So, you're almost a different person. You think differently. You articulate differently. You're just different, so it is easier to deal with. (P6)*

*Because I was on a methadone script, she kept saying to me, "I need you to open to me, we need to get down to it," and I was thinking, "Well, I can't, because my emotions are not the same." When you're on methadone or when you're on heroin you're not your real self, so you can't... You haven't got your true emotions, so you can't open up properly (P6)*

The OST patient went on to state that from personal experience, he found that counselling was more beneficial during periods of abstinence:

*It would be more useful, yeah, definitely. That's what I found [referring to personal experience of benefits of counselling during periods of abstinence from heroin], anyway. (P6)*

However, the *setting* barriers of unavailability of counselling on site and long waiting lists for counselling could mean that counselling is not delivered during the optimal period of clarity:

*Whereas now, we don't have that counselling capacity in (name of Drug agency), so I can't do that now really. And because I don't get supervision, it wouldn't be ethical for me to touch on that particularly, so I have to refer people on to New Pathways, or Cruse (S6)*

*No, because the issue is, our workers aren't referring in to community counselling services, because the wait is so long, and also, that service user is really unlikely to turn up there because they're chaotic. So, we've got to meet the needs of service users, rather than the needs of the service. (P32)*

Therefore, the *drug* factors (effects of Buprenorphine) interact with *setting* factors (access to treatment) to become potential barriers and ultimately affect the wellbeing of the OST patient (a *set* factor) (i.e. a torturous state where the OST patient is forced to confront his/her emotions with no access to counselling). This suggests that provision of counselling (*setting*) on-site for those on Buprenorphine, could help promote progression in treatment. Indeed, one staff member described that on-site, in-house counselling had worked well in the past:

*So, I remember myself sat in an assessment, and a service user may allude to childhood sexual abuse. I could go up, ask [name of counsellor] to come down. [name of counsellor] would come downstairs, she would chat to the client, and then make an arrangement and give that client a date to come in and do six or eight sessions around that trauma, and we saw really good results when we had [name of counsellor] in service. (P30)*

This uncomfortable flooding of emotions was not confined to the enforced abstinence of Buprenorphine. A staff member stated that it was also commonly experienced by many OST patients with histories of adverse childhood experiences who had decided to stop their use of heroin:

*A lot of them have used heroin to block out adverse childhood experiences, as ways of coping with sexual abuse, domestic violence as children, bullying. I think that when they stop using drugs or try to get clean, they often can't handle having to relive what they've been blocking out. (S9)*

## **Solutions**

One staff member felt that the provision of in-house counselling would be beneficial generally and not only for those on Buvidal. This is because some OST patients can become dependent on the drug services for other kinds of support including emotional support:

*... people can become quite dependent on our service. They come to us for food parcel forms, housing support, everything, and I do think they would probably benefit from an in-house psychosocial support, a proper counsellor. (P9)*

However, this dependency on drug services can itself become a barrier for reintegration within society (a key outcome and indicator of success) because service users are required to attend the service regularly to pick-up their scripts and therefore, remain in contact with their drug-using networks, members of whom are also attending the service. Moreover, the fact that they are often seen together, congregating in the same locations, and sometimes acting antisocially might reinforce the stigmatised views that are so often attached to problem drug users. What services could consider doing instead is to empower these individuals to become independent and less reliant on the support provided to them by drug services:

*We're keeping them close to protect them, but actually we're making things worse, because what happens is they all congregate in one area, they're altogether, and then they're seen as antisocial and a nuisance and all the rest of it. But what we should be doing is kind of getting them to spread their wings, and kind of move on I suppose. (S14)*

The discussion above suggests that the barriers to successful treatment that might be generated by the prescribing of Buvidal could be overcome through appropriate and easy to access counselling provided by support services. Nevertheless, this psychological support needs to empower service users to become independent rather than further making them reliant on support. This suggests there needs to be a balance between accessibility of services and achievement of integration.

### **6.3. Heroin-related reasons/motivations**

In addition to barriers related to the existence of withdrawal symptoms and effects of Buvidal, participants in this study discussed several other drug-related factors which impeded their successful OST treatment experience. These included: (1) using heroin for self-medication, (2)

enjoyment of the effects of heroin and (3) the quality of heroin available on the market. Each of these are discussed in detail in the remaining sections of this chapter.

### **6.3.1 Using heroin for self-medication**

Many participants (including both staff and patients) reported that the use of heroin (*drug*) helped to alleviate emotional pain and symptoms of trauma and abuse (Zinberg, 1984):

*I think I started using heroin because of things in my past and stuff, (P2)*

*A lot of our clients, I wouldn't be able to put a number on it, but I think there's a large proportion of our clients who have experienced abuse or some sort of trauma in their life, and I think they use drugs as a coping mechanism to deal with the effect that has on their mental health. (S18)*

The use of heroin to cope with traumatic experiences was described by one staff member as leading to the development of the 'schema' that heroin is an acceptable and useful way to cope with difficult emotions:

*So obviously, as you go through life, any sort of difficult situation, the schema pops out and says "ah, this is what we do; this is how we deal with it." (S11)*

One patient noted that this association between stressful situations and the use of heroin as a coping mechanism is always present:

*If anything made me angry, I'd just go and use and that would be okay. If anything made me sad I'd go and use, and I'd be okay. So, very quickly, there's a very strong association being built up there, isn't there, I suppose. Stimulus and response, isn't it? Yeah, I think that becomes very, very powerful and very, very hard to break.... Even when you overcome it, I think it's been always there. It's almost like a virus. It lays dormant in the system until something triggers it. (P25)*

Some OST patients described how the occurrence of emotionally charged situations led to the use of heroin:

*It's just if something bad happens. I've got to be careful a bit because that's why turned to it before. (P33)*

*Oh like, losing family members, you know, that's what has always brought me back to the drugs. (P8)*

*I come off everything. I come off it. I come off everything and then I lost my mum then and that spun me back then and then... it was like I was in an avalanche. I lost... within a year, I lost everything. (P8)*

*As soon as mum passed away, I went straight out and injected it. I haven't done it for about three weeks. (P12)*

*I slipped again and then come up here, got clean again, and then my mother passed away and that's why I used heroin, (P16)*

*I just used in prison, I hadn't used for a while then, and my father died, and I started using again. (P33)*

For one patient, the bereavement resulted in additional funds that were used to pay for pain-numbing heroin use:

*Yes, because my mum died, automatically she had... I think it was something like thirty grand in the bank, so me and my sister had fifteen grand each, so straight away then I have the funds to go back to the drugs and just numb the pain like. (P16)*

Importantly, bereavement was blamed by some patients wholly for the return to the use of heroin or prescription drugs:

*I know for a fact if mum hadn't died I would never have gone back onto it, and I struggled for a couple of years then, and I got arrested for a burglary which was nothing to do with me, never got charged (P16)*

*I would never touch a drug, because drugs for me lead me to not a good place. Having said that, I would touch prescription drugs when my mum died, but ... it was what I needed at the time (P32)*

## **Solutions**

To progress in treatment, a staff member explained that OST patients need to learn to cope with stress without resorting to the use of drugs:

*We need to be able to get you to think about unhappiness, and trauma, and difficult situations without resorting to self-medication...But let's get you to a position where you can live what you call a normal life, but be able to deal with problems in a different way. (S11)*

A further solution to address this use of heroin as a coping mechanism, could be the use of non-punitive interventions by treatment services that target the underlying reasons for consumption of the drug:

*... just talk to them, and obviously ask them why they went down that road, or why they're using, do you get what I mean? But just don't lose your patience, basically, because people will open up. (P2)*

*Not simply punitive, yeah. You need a punishment, but you've got to say why? "Why do we need to punish him? Why has his behaviour got to such a state where he needs to be punished? What's causing his behaviour? (P10)*

*Like I said, you need to deal with people's underlying reasons for why they're in drug use in the first place, to fix it, otherwise it's just a waste of time. (P6)*

Some participants suggested that the prescription of substitute medication might be inappropriate during periods of emotional pain, because of continual use of heroin. For instance, the use of heroin with substitute medication could substantially increase the risk of overdose:

*Because every now and then a strong strain could come through and if you're on say seventy ml of meth and you have a strong bag of gear, you're gone, you know? It's dangerous as well but it doesn't happen regular, often, but it does happen. (P4)*

It was suggested that, instead, OST patients should be offered support in the form of harm reduction measures such as provision of safe injecting information, prescription of pharmaceutical heroin and the use of safe consumption rooms:

*... there are some people on methadone at the moment, and maybe they're having a catastrophe, and actually, being on methadone is not the right place for them to be, you know what I mean? And it could be that the problem is, for instance, they may have had bereavement ...But we should be teaching people how to do things safely, because if you can teach someone how to inject safely, then you're going to cut down on abscesses but for those people perhaps that's not the answer and perhaps things like injecting rooms and pharmaceutical heroin is the way to go with those specific clients (S14)*

It was thought that providing access to harm reduction support during periods of stress could

help stop the revolving door of OST patients and promote continuity of contact with them:

*Yes, I think we'd have more success with that ... than the way things are at the moment. I'm constantly having people in and out of treatment, but if you're able to move treatment programmes, at least that way someone's not dropping off the face of the earth, and at least you still know what's happening with them, and you know how they are (S14)*

One staff member suggested that if bereavement is a trigger, mindfulness techniques (*setting*) could also be used to teach skills to cope with depression associated with bereavement:

*I'll just use little sort of mindfulness techniques; ...the dark cloud, you know the raincloud, you know the fact that we can have rain at any time. And with mindfulness, when a bad memory becomes a black cloud, it sits overhead, and you sit there and you look at it. If you focus on it and start to relive it, and start to get absorbed by it, you walk around all day with that cloud over your head, and that's where the depression and anxiety comes from et cetera. It's getting the skills to recognise the dark clouds for what it is, and then watch it go. (S11)*

Peer support (*setting*) was also identified as a solution to address the use of heroin in response to stressful situations, as it can provide powerful mutual support and elicit alternative mechanisms to cope with emotional discomfort:

*And another one will say "I really struggled, either I used, or I drank, or I really wanted to use," and the support that would come from those who'd had a good weekend; I'd just sit back and watch the ideas, "oh yes, I felt like that last week." "So what did you do?" "Well what I did, whenever I feel like that I do..." and you can see them feeding each other. (P11)*

The use of heroin by many OST patients in response to emotionally charged situations highlighted the importance of treatment services in understanding what was important in the OST patient's life and identification of negative emotional states. This could then pave the way for implementation of appropriate interventions such as provision of harm reduction advice, visualisation techniques and peer support. This could in turn help to address the barrier of using 'heroin for self-medication' purposes.

### 6.3.2 Using heroin for pleasure

The pleasurable effects of heroin are classed as *drug* because they are related to the pharmacological experience of the drug (Zinberg, 1984). A few OST patients described the powerful effects of heroin in the following way:

*Well, I'll be quite honest with you, when you first take it, it's lovely. That's the only way to explain it. It's better than sex. It is. It's unbelievable the feeling you get off it. (P12)*

*Yeah, it's like your Ready Brek life. (P28)*

*That feeling, that first ever feeling, it was like nothing I ever experienced before in my life. So nice. It was so nice. (P19)*

*You feel as though nothing's going to hurt you, and you're like wrapped up in cotton wool. (P27)*

*It's sort of... when I inject it, there's a real warm feeling all down my face and down through to the inside of my body, through my core. It feels like my core or my soul is being warmed up and everything around me becomes trivial. (P36)*

A staff member acknowledged that it is difficult to enhance motivational levels for OST patients who are still experiencing the pleasurable effects of heroin, while engaged with OST:

*We also cannot discount the idea that they actually like what they are doing for themselves - and therefore the intervention to improve motivation to change becomes an uphill struggle. (S15)*

This enjoyment of heroin and the lifestyle associated with it was known to prevent progression in treatment particularly when OST patients are compelled to attend treatment when they still enjoy using the drug:

*... and to try and break that cycle is not easy by any stroke of the imagination. And they have to be ready to change and have motivation and support on the way to do it. And to be honest, some like the lifestyle; some like using heroin, and I think we've got to remember that.... And especially with criminal justice, they are made to attend when perhaps they don't want to. (S8)*

### Solutions

The interviews highlighted that the continual experience of pleasure from heroin could prevent achievement of benefits from OST. A staff member stated that one solution could be the

adoption of a punitive approach which involves detoxification of substitute medication and discharge from treatment. This is because the purpose of the use of substitute medication is redundant, when the OST patient does not want to stop the use of heroin:

*Let's detox you and come back when you're ready, not when you think you're ready and it's just lip service. It doesn't always go down well, but I just don't see the point of adding in a treatment when they don't want to and are using on top. (S8)*

However, the solution of 'discharge from treatment services' could be problematic because it means that the OST patient would not be in contact with treatment services after detoxification and could reverse any progress achieved on the treatment journey:

*They've been kicked off because of it. There's no winner by there...because all they've done is kicked somebody back six, eight months. (P34)*

Importantly, OST patients are also at increased risk of overdose following discharge from treatment.

The discharge from treatment services could also strengthen the 'revolving door' where OST patients are cycling in and out of treatment services, without gaining any benefits from OST. The staff member stated that a better option would be to retain OST patients and work with them on a continual basis:

*... but then they just end up in a repeat pattern of repeat offenders when I think we're probably better off just keeping them in treatment, holding them and working with them. (S9)*

Provision of long-lasting non-drug replacements from the start, was described by a staff member as essential to enable progression in treatment:

*If you're going to take drugs and alcohol out of some people's lives then we've got to replace it with something, and that something's got to be there, not six months later because that leaves a chance to relapse or what-have-you doesn't it? (S15)*

For example, mountain biking now provided an abstinent OST patient with excitement:

*If it makes me feel good, I can do it to excess. I do still do silly things, like off-road mountain biking. I can go fast down very steep mountains. That's going to stay. You've got to have some excitement, haven't you? (P25)*

The continual prescription of substitute medication during periods of heroin use, was deemed to increase the risk of overdose. However discharge from treatment could also reverse achievement of progress in OST, increase risk of overdose and strengthen the 'revolving' door of OST patients. One potential solution to resolve this dilemma, could be the provision of harm reduction interventions during the periods of heroin use, as articulated by participants themselves.

#### **6.4 Quality of heroin**

The third drug related factor of 'quality of heroin' was deemed to be a barrier in the achievement of success in OST by participants. In line with Zinberg's framework (1984), the quality of heroin has been classed as a *drug* factor that was found to act as a barrier to treatment success. Participants identified that the potency of heroin can be an influential factor in whether an OST patient is benefiting from treatment or not. Interestingly, interviewees reported that both low and high quality of heroin could have an important effect on treatment success.

A number of OST patients identified that the purity of heroin has declined with time:

*They call it smack because it gives you a smack round the head, well it used to, but it doesn't no more. (P4)*

*I could go and buy one now and it won't be as strong as the methadone and it won't touch me. (P12)*

*The quality when I first started many, many years ago, gear was really strong then but now they mess about with it so much, you don't know what you're smoking really. (P15)*

*It was mixed, but not as much as what it has been mixed with today. There's a lot of ... a lot of, I don't know, garbage going on in there, but when I started smoking, we were smoking, like, tidy things. (P20)*

*It's all b\*\*\*\*\*s. Rubbish. Rubbish stuff now. (P34)*

The lower quality of heroin meant that more quantities of heroin were needed to alleviate withdrawal symptoms, which in turn placed more financial pressure on the OST patient:

*One bag won't stop the clucking.... I'd gamble that they've got to get at least two. At least two. That's £20 a day. That's a lot of money in a fortnight. Basically, that's a lot of people's giro gone before they buy electric, gas, anything like that. (P34)*

It was noted that financial pressure could in general, lead to engagement in offending or sex work and affect the wellbeing of the OST patient:

*Oh dear, I haven't got any money, this is getting out of hand; I'm going to have to go and do something now; I'm going to have to go and rob someone or do something bad, or sex work or whatever it is you know? (S13)*

Powerful imagery was used to describe how changing the quality of heroin (*drug*) is used as a tactic by drug dealers (*setting*) to re-initiate and strengthen the cycle of dependency:

*It's a little bit better over the last two months, but then all of a sudden, when I've used it, is it gets better and then once... it's like reeling you in. It gets better and then they bash it. (P12)*

The deep entrenchment in the drug-using lifestyle through engagement in sex work/offending and strengthened dependency could result in the missing of appointments:

*If you've got clients that always turn up to your appointments, and then all of a sudden they start missing, then obviously you know there's something wrong. (S3)*

This non-attendance at appointments is problematic because it could result in the loss of substitute medication:

*I missed loads and I ended up losing my script (P36)*

However, the low purity of heroin was not always a barrier to success. Indeed, it motivated one OST patient to stop his use of the drug because he no longer experienced any enjoyment:

*They're cutting it so much; it's just no point in doing it, seriously. (P4)*

The stronger quality of heroin was also deemed to be a barrier to treatment success. The increased tolerance associated with good quality of heroin, meant that some OST patients had to use more and more heroin, because even at high doses, the OST medication was not effective:

*I was on 100ml of meth and taking this really good f\*\*\*\*\* heroin on top of it. So, I just had a massive tolerance as well and... it's just like not even having the script at all, because you haven't got the baseline anymore. (P36)*

## **Solutions**

The low quality of heroin was reported to affect OST patients in different ways. In some circumstances, it led to increased use of the drug, increased financial pressure, strengthened dependency, missed appointments and, in some cases, discharge from treatment services. In other instances, the low quality of heroin led to cessation of heroin use and achievement of success in treatment. Stronger quality of heroin was associated with increased tolerance levels, which for some reduced the effectiveness of OST.

This impact of the quality of heroin on the life of the OST patients' lives, suggested that staff members need to be aware of factors that could impede progress in treatment. Participants highlighted the importance of staff members in getting to know what is currently happening in the OST patient's life. This could ensure that the OST patient receives the appropriate interventions or advice that are best suited to their needs:

*just take a bit more time to understand what that person is going through before you engage what you're going to say to them. (P35)*

*The more time that you can actually have with a person and know the nitty-gritty and the ins and outs of their lives, where a professional might think "Right this is what I need to work on with him, this is what I need to do for following through with him" and stuff like that. (P36)*

*So sometimes you've got to tweak things, and obviously you've got to know your clients as well at the same time. (S3)*

However, it was recognised that this approach could be costly. Indeed, one OST patient acknowledged that limited financial resources for service providers could mean that staff members are unable to spend as much time with OST patients as they would like:

*But obviously at the end of the day, with money and resources, there's obviously only so much anyway, isn't there? (P36)*

This highlights the important issue, that treatment services are often faced with the need to work within a tight budget. However, in a similar vein, investment in time and financial resources in getting to know the OST patient could initiate progression in treatment and save money in the long term. The impact of purity levels on achievement of benefits from OST also highlights how important it is that treatment providers are aware of current purity levels of heroin use. These findings imply that OST patients may need different interventions depending on their individual responses to changing purity levels.

## **Conclusion**

In this chapter, *drug*-related barriers that prevented optimal achievement of benefits from OST were identified and potential solutions offered by the interviewees were presented. For clarity, the barriers (and solutions) were grouped into four key themes, namely: 1) withdrawal symptoms, 2) the effects of Buprenorphine, 3) motives for using heroin, and 4) the quality of heroin.

In relation to withdrawal, the extreme discomfort of withdrawal during titration, fluctuation between stability and withdrawal, and lengthy periods between doses resulted in continual use of heroin to alleviate these symptoms among some patients. With regard to the effects of Buprenorphine, its blocker properties led to enforced abstinence from heroin and were noted to produce a clarity of mind not evident when on heroin. For some, this clarity of mind became a barrier to achievement of benefits from OST in the absence of appropriate support. This highlighted that there is an unmet need for counselling and a generic need for OST patients to address the root causes of their dependence.

In relation to motives for use, the entrenched schema that heroin will alleviate pain resulted in continual use of heroin while receiving OST in the absence of adequate support. Furthermore, the pleasure gained from heroin was a barrier to achievement benefits from OST, because OST patients were compelled to attend appointments when they were still enjoying the effects of the drug. Finally, the quality of heroin impacted on treatment success in several ways. High quality heroin was associated with increased tolerance levels, which in turn had an adverse impact on the efficacy of substitute medication. Low quality heroin meant that more quantities of heroin

were needed, which in turn placed financial pressure on the OST patient. This financial pressure could motivate some OST patients to engage in offending behaviour or sex work.

One key finding was that the *drug* barriers affected achievement of benefits from OST in the absence of appropriate psychosocial support. This finding is consistent with Orange Guidelines that underlined the importance of effective psychosocial interventions in supporting the recovery of OST patients (Department of Health, 2017). The impact of the absence of appropriate psychosocial support is demonstrated by the complex interaction of *drug, set and setting* factors, in relation to the effects of Buprenorphine. For example, the blocker properties of Buprenorphine (*drug*) means that the OST patient is likely to stop the use of heroin. This enforced abstinence results in flooding of uncomfortable emotions (*set*) which can affect the wellbeing of the OST patient in the absence of appropriate support (*setting*). In turn, this resulted in a torturous state where the OST patient is forced to confront his/her emotions with no access to counselling.

Important changes in the delivery of treatment could result in improved outcomes for OST patients. Prescription of Buprenorphine, additional wraparound services, support from the GP and take outs of substitute medication could help to address the barrier of withdrawal during titration and the period between doses. The clarity of mind that is associated with the administration of Buprenorphine could be addressed by the provision of onsite counselling. However, the delivery of counselling services within drug treatment services could be a barrier to reintegration of OST patients with society. This is because the provision of support services within drug treatment services could encourage congregation of people who use drugs and further reinforce stigmatising perceptions of people who use drugs. This raises the important point of whether treatment services should provide onsite counselling or develop partnerships with external counselling services to meet the needs of OST patients. Similarly, the remit of the role of the prescribing doctor in providing support for the treatment of non-drug related health issues is unclear.

The entrenched schema that heroin will alleviate emotional pain could be targeted by treatment services, through the provision of harm reduction support, addressing reasons for heroin use,

visualisation techniques and peer support. Treatment through the services could respond to the pleasurable use of heroin through the provision of alternative pleasurable diversionary activities such as mountain biking, cycling etc. The varying effects of quality of heroin on treatment success could be addressed by staff members spending more time with OST patients. However financial constraints could affect implementation of this solution. The counter argument could be that investment in time and financial resources, could promote progression in treatment and save money in the long term.

Overall, it is clear that a range of *drug* barriers prevent achievement of benefits from OST for some patients. However, a reassuring finding was that these *drug* barriers could be addressed by treatment services to promote progression in treatment. One key finding was the important role of determination to succeed and readiness to change achievement of success in treatment. The challenge is finding ways of helping patients to get these mindsets. The next chapter will explore '*set*' related barriers that could a) prevent achievement of success in treatment and b) potential solutions that could improve the wellbeing of the long-term OST patient.

## CHAPTER SEVEN - *Set* related barriers

### Introduction

The previous chapter drew upon the interview data to examine the *drug*-related barriers to treatment success. This second results chapter moves on to focus on *set*-related barriers. *Set* is defined as “the attitude of the person at the time of use” (Zinberg, 1984; p.5). Psychological factors such as previous experiences of drugs, mood, motives, and expectations of the person who uses drugs can also be described as *set* (Jansen,1997; Lau et al., 2015, Mui et al., 2014). Participants in this study stated that the following *set* barriers prevented achievement of success in OST: 1) low levels of confidence 2) mistrust of treatment services 3) vulnerability 4) lack of readiness to change 5) limited personal responsibility and 6) shame. This chapter also presents solutions that could help to overcome these *set* barriers, as elicited from the participants themselves.

### 7.1 Low levels of confidence

Long histories of drug use meant that for some patients, drug use and associated behaviours had become normalised. Thoughts about stopping their ‘normal’ routines and behaviours were a source of anxiety for some patients, who after years of habitual use had little confidence in their ability to stop using and succeed in treatment. Confidence is an emotional state of mind (i.e., a *set* factor (Lamonica et al. 2021)) and a low level of confidence was identified as a barrier to treatment success among some patients.

A staff member and an OST patient acknowledged the difficulties of stopping heroin and substitute medication faced by some OST patients with long histories of either drug use or OST treatment.

*For however long it’s been, either using heroin or being in treatment for the majority of their life, for me then to say, “You could do without this.” If this has been part of your life for three quarters of your life, for me to then say, “Start reducing, come off it,” again if I put myself in those shoes, I’d be freaking out. “There is no way I’m coming off this substance. No way.” (S16)*

*It takes ... you know years for somebody to get in that mental frame of mind to get clean from gear and yeah so, my anxiety at the moment is there. (P5)*

OST patients stated their low levels of confidence and perceived ease of drug use in comparison with the difficulty of achieving abstinence, resulted in their continued use of heroin:

*I am just finding it difficult to get off it because my anxiety levels start to rise and then I don't feel right. I don't feel my normal self... I feel as if I am going mad. (P5)*

*...because when you start off on a script and all this and that you just think, "How the hell am I going to..." It's just so daunting (P6)*

*Because you know that stopping that drug use is going to be a lot more difficult than making a raise and going and getting another bag and feeling better again. (P32)*

A staff member explained that some OST patients continued to use heroin because of their low confidence surrounding integration with society. The continued use of heroin then provided an excuse for them not to integrate with society:

*In a way if they're on opiates then they've got an excuse for themselves, because I think they're scared of entering the sort of everyday society really. (S20)*

## **Solutions**

A solution offered by an OST patient was that more time is needed in treatment to address the issues associated with anxiety of abstinence and long histories of drug use:

*...but I feel for people who have doing this for years and years ... we need to be in treatment for ... what's the word I am looking for? We need to be in treatment for a longer period if you see what I mean (P5)*

Another staff member stated that acknowledgement of difficulty of abstinence could help to address that barrier of low confidence or fears surrounding abstinence:

*And I think it's just us sometimes acknowledging how difficult it is you know? I think it's tough and just understanding that sometimes. (S6)*

To improve confidence in achievement of treatment success, a psychosocial keyworker stated that he used visualisation techniques (a *setting*-related factor) and worked with patients' existing strengths to enable them to build a personalised and detailed picture of abstinence:

*... helping the client build that picture and really filling in the colour and the detail. ... The whole thing about visualisation is that if you can actually build that picture and start to fill in the detail around it, so what these changes are actually going to make, yeah? By making that picture more desirable than the current picture your subconscious starts to move towards it, you start to work towards it, actually consciously. Working with what they've got rather than looking at what they haven't got. (S15)*

Another staff member stated that he enhanced confidence levels by empowering patients to access professional support (a *setting*-related factor) independently while engaged with OST:

*I try my best for them to take their own ownership, because obviously when they are abstinent, they will have to decide themselves, they'll have to do things themselves, so sometimes it's best to start them off while supporting them at the same time. It's like if somebody needs a GP appointment for example, because a lot of the time it can be difficult for the actual individual to make that appointment, so I would encourage them to do it so they would get used to it. (S3)*

Other solutions to address low levels of confidence and help to resolve fears of abstinence included showing OST patients a) the value of abstinence and b) that abstinence is achievable:

*I think the best thing you can do is you need to show people that it's worth doing, and it can be done. (P6)*

The OST patient elaborated and stated that the value and achievability of abstinence could be shown, through the employment of staff who experienced difficulties with drugs in the past but have now achieved success:

*So, again, it goes back to having counsellors that have been there and done it, making people believe that it is worth doing and you can do it (P6)*

Therefore, the use of visualisation techniques, preparation for abstinence through empowerment and increased visibility of positive treatment outcomes could enhance confidence levels, which could in turn promote progression in treatment.

A staff member explained that adverse childhood experiences (ACEs) are often associated with lack of belief in the OST patient, which could have a negative impact on self-esteem and hence on treatment outcomes:

*You know there's a dark understorey with these clients where they've had really, really difficult upbringings; nobody's believed in them, their lives have been s\*\*t, and part of them wants to give up; part of them actually just wants to give up and die a lot of the time actually, and they're struggling with all of that as well. So, when they fail, all those kinds of demonic voices are back saying "you're always a bit of a loser; what's the point of trying?" and you're up against that. (S17)*

This quotation implies that for those with ACEs, lapses of use of heroin or perceived failure in treatment could have an adverse impact on resilience levels to 'bounce back' and progress in treatment.

An OST patient explained that the doctor's sense of humour helped to improve his confidence levels and promoted continuation of success in treatment after the lapse:

*The doctor not to make me feel so bad he made a bit of joke out of it to try and lighten it up. Come on [participant name]. It is not as bad as you think it is... He cheered me up about it. He said come on we can start from here now. And that's what we done. I haven't seen him a great deal, but the doctor is amazing.... We all make mistakes. Come on and we had a little laugh about it and that. (P26)*

The low confidence levels of OST patients could be attributed to prolonged use of drugs and ACEs. The absence of visibility of treatment successes within drug treatment services could strengthen the mindset of OST patients that recovery is not possible. This suggested that treatment services need to be attuned to low confidence levels of OST patients, in the achievement of success in treatment.

## **7.2 Mistrust of treatment services**

A third *set*-related barrier to treatment success that emerged during the interviews with staff and patients was the lack of trust in treatment services felt by some OST patients. Feelings of mistrust were linked to five important factors, namely: lack of belief that issues will be resolved, lack of visibility of treatment success, anxiety of losing prescribed medication, ACEs and inability to trust others and mistrust of staff members. Each of these issues will be discussed in the sections below.

### **7.2.1 Lack of belief that issues will be resolved**

One staff member explained how previous negative treatment experiences could facilitate a sense of distrust amongst some OST patients in the current treatment episode:

*It may be the thought on the part of the client that this is the treatment I have gone through before; it hasn't worked last time so why should it work this time? (S15)*

A similar point was also made by an OST patient who explained that he would not disclose personal issues to his current keyworker, because previous disclosures to a similar person had not helped him/her progress in treatment or address his mental health issues:

*You know... I am not getting into anything deep with her, because I have gone in deep with other keyworkers here and I am not getting the treatment that I need. I just hold back... sod it. (P5)*

*... they are not getting the support and help to deal with their mental state you know for their mind and things like that. And this why a lot of us at our age fail... keep failing all the time and you constantly in and out of treatment all the time. (P5)*

The mistrust and reluctance to share information were identified as barriers to progress, particularly in psychosocial sessions where openness is needed for patients to fully benefit and make progress:

*I want you to be able to feel that you can tell me anything, because at the end of the day we're not going to progress until we're on the same page. (S11)*

Staff members stated that the brief 'check-in' approach of keyworkers in previous treatment episodes, meant that delivery of evidence-based interventions (e.g. motivational interviewing, cognitive behavioural therapy) by keyworkers in the current treatment episode, triggered feelings of mistrust:

*When I first started working with substance users, I found it quite difficult to get them engaged. Because with the previous workers, they'd come in, just check in, see if the script's okay and that was it, gone. And I'd say, "Well we need to do some work here". And now, well, "Such-and-such said that I only need to come and check in with you and to make [sure] my script's okay". (S1)*

*And so, they've had different key workers, so they've probably experienced a lot of different ways of the treatment, and how to engage with them and things like that. (S4)*

This mistrust of the need for and usefulness of more intensive interventions in current treatment episodes (influenced by previous less intensive treatment experiences) is classed as a *set-related* barrier to progress. This is because it made it difficult to encourage patients to engage and subsequently wasted valuable time.

*I think it's hard to promote change with them and keep the motivation to things. When they come into service, say four or five people who I've had, one man in particular; he's been on Buprenorphine since 2014, and when you try to challenge him on dosing, or "can you ever see yourself without this?" and they're like "no," because they've been on it for a long time. They will depend on it, not only physically, but I think when they've been here for a while, and had different key workers and things, and no one has challenged change previously. (S4)*

*When that happens, I think with some of the clients it probably took me probably between six and nine months to get them to realise this is a session we're doing. It's not just about checking in to say your scripts alright. It's what can we do to change. (S1)*

This discrepancy between delivery of evidence-based interventions and check-in approaches could partially be attributed to the perception of some staff members that informal sessions were more suited to the needs of people who use heroin:

*I absolutely believe that drug clients, not alcohol necessarily, benefit from a shorter 10-minute chat than trying to force someone to sit for half an hour or an hour. (S9)*

A staff member stated that the formalised delivery of psychosocial interventions meant that it was difficult to understand what was happening in the life of the OST patient:

*Now it's, "Come in, get your meth, please leave, don't bring your children, turn up for your 10 o'clock appointment." It's like an army camp. (S9)*

## **Solutions**

Clearly, the failure to address mental health issues in the previous treatment episode contributed to mistrust in the current treatment episode. This failure to address mental health issues could be attributed to the finding that staff members are not adequately trained to address mental health issues at present:

*I sometimes get the feeling that the psychological needs of the hardcore heroin user are much deeper than perhaps the skillset which our organisation has attracted actually allows. (S15)*

To help prevent the development of mistrust, an OST patient highlighted the importance of training staff members (*setting*) to identify mental health issues and provide signposting to relevant mental health services if needed:

*Going back to mental health, like I just said... they need to be trained... the keyworkers need to be trained in mental health and being able to see it or even to say right we need to make an appointment for you with the mental health doctor or whoever it is. (P5)*

The introduction of medically-based triages (*setting*) could also enable the early identification of physical/mental health issues:

*I feel it would be more beneficial if they're seeing a medic or a nurse, and then we could say "hang on a minute, this person does have ..." You know some of the things that you hear that come from the engagement side of things, you'd think well, this person needs to go to so and so, and it's a different step for a nurse, or a social worker, or a doctor to ring up the mental health team and say "you do need to see this person, and you need to see them now." (S13)*

The need for identification of mental health issues and training of staff members was also highlighted in Chapter 6, which identified that Buprenorphine OST patients who are making progress may need support to address the flooding of emotions that can occur when heroin use stops.

The adoption of an informal approach could help staff members understand more what was happening in the life of the OST patient and the motivations of the OST patient, which could in turn affect promote progression in treatment:

*You find out more about people's lives when you've got that. (S9)*

*They're more willing to divulge information, be honest with you, reminisce on the past. It gives you a truer picture of their motivations, where they are in their own head. (S19)*

Both S9 and S19's perspectives resonated with my own experience of interviewing OST patients, as some participants expressed a preference for interviews in informal settings (as discussed in methodology chapter).

As explained earlier participants were divided on whether the delivery of formal or informal interventions were more suited to the needs of OST patients. These conflicting views of whether evidence-based interventions or informal sessions are more beneficial in improving the wellbeing of OST patients, suggests that interventions need to be individualised to meet the specific needs of the OST patient. In fact, a staff member stated that some OST patients might be more suited to informal support, while others are more suited to formal interventions. Therefore, one solution could be to match OST patients with an appropriate staff member:

*So, for example, there are some people who have certain ways of working. They are very rigid and sometimes, you need rigid structure for certain types of clients and others, a rigid structure won't work. But unfortunately, everybody gets to go to and see the rigid structure in that particular area, while another person might be very formal, little chat here and there, not really any formal. But it works well for some people. Yeah and... for some people that's not structured enough. So, I suppose in an ideal world, you would have different tiers of key workers, you know, very intensive and... and, you know, some who are specialists in certain areas. (S7)*

Some staff members also identified video assessments as a useful tool for ensuring that interventions are delivered consistently and in accordance with the principles of therapeutic interventions. It was felt that this method could help to reduce use of the 'check-in' approach and subsequently overcome the difficulty of initiating change in the current treatment episode. Videotaped assessments would also help to make sure that staff members are accountable for the content of psychosocial sessions and ensure that they are used appropriately:

*One of the really good things that we've done in the last 2-3 years is brought in mandatory video assessments of our case work with clients to be viewed by our training department and by our managers as well, because it makes us all accountable. (S15)*

*It's one of the improvements that the organisation has made is that it's made us accountable for what we do in sessions and make sure that we're actually using the interventions and using the skills that we're supposed to have competently and confidently. (S15)*

An added advantage of the use of videotaped assessments is the opportunity for keyworkers to improve their practice and skills through the development of increased self-awareness and reflection. This could, in turn, help OST patients to move forward in treatment:

*Well I think it just makes you aware of how you apply your skillsets, and to have somebody to be able to analyse that and feedback to you, but also to actually watch it yourself, where you can actually look at your body language, look at your facial expressions, see how well or not well you structure the session, see the points where you might be losing the client, like the highs and the lows. (S11)*

*Think making the key workers aware of their practice and giving them the ability to make improvements on their practice. (S11)*

Trust in the efficacy of treatment services is important and needed because it could facilitate receptiveness of OST patients to the delivery of interventions, which could in turn promote progression in treatment. As seen from the above discussion, mistrust of OST patients manifested in various ways and affected achievement of benefits from OST. The previous experiences of inaction upon disclosures of personal issues and inconsistency in delivery of approaches clearly contributed to a mistrust of psychosocial interventions among some patients. The conflicting views of whether formal or informal interventions are more suited to the needs of OST patients, could be resolved by matching OST patients to the appropriate keyworker.

### **7.2.2 Lack of visibility of treatment success**

A second *set*-related factor that contributed to feelings of mistrust was the absence of (or invisibility) of people achieving positive treatment outcomes:

*I know lots of addicts and people who are on scripts and stuff, and when you think about how many of them are actually clean, got on a script and got clean, and are living a normal life, there's just nobody really, hardly any. So, when you see that, there doesn't seem much hope. "If nobody else can do it, hardly anybody else can do it, how am I going to do it?" So, they need to see more positive outcomes, that it can be done, it is achievable. (P6)*

*But I don't see many success stories...(S19)*

Therefore, the absence of known success stories in treatment services (*setting*) contributed to the mindset and mistrust (*set*) that the achievement of success within OST is not possible.

## Solutions

To address this barrier of limited visibility of positive outcomes, it was suggested that people who have achieved success in employment, education, relationship etc, despite previous difficulties with drugs could be invited to treatment services:

*It would be nice to have someone to sit down in front of you who's been a raging druggie and on the streets for 10, 20 years, and then sit down in front of you, "Look at me now in my Armani suit, I've got my own business." (P6)*

Similarly, recruitment of staff members who have overcome their difficulties with drugs could help to increase trust in the efficacy of treatment services by showing that the achievement of recovery is possible:

*I think the best thing you can do is, you need to show people that it's worth doing, and it can be done. So, again, it goes back to having counsellors that have been there and done it, making people believe that it is worth doing and you can do it. (P6)*

*I got there, the head counsellor was a recovering alcoholic. All the staff were recovering addicts. I was in a house with 25 other hopeless junkies, and I sat there after the first week, syringe and everything still in my bag, I hadn't decided whether I was going to give up or anything, and I thought, "Well, God, if these people can do it, sure as hell I can." It had a massive and profound impact on me. (P25)*

Interestingly, one patient explained that that the positive role model need not necessarily have any previous involvement with any drugs:

*So it doesn't necessarily have to be someone from a drug background, but maybe someone around the same age as them, or someone who likes the same band they like; just someone who they can kind of think "right, okay, well if you could do that, then I could do that. (S14)"*

Normally in therapeutic sessions, self-disclosure is not encouraged because it detracts attention and time away from the OST patient. However, one OST patient stated that self-disclosure in some circumstances could help to enhance the visibility of recovery and provide invaluable knowledge that the staff member has been in a similar position to the OST patient but has now achieved success in treatment:

*P: But, certainly when I worked in services, we weren't allowed to disclose our personal experience.*

*SK: What are the benefits of disclosure?*

*P: Making recovery visible, isn't it? They don't need to go into any depths of the stuff that they've done, or how bad their life was, or even what drugs they've used, but just enough to know that that person has walked their path, and has managed to turn their life around. ...As long as they're not putting that on the client saying, "You must do it the same way that I've done it," but just saying, "This worked for me. Maybe it's something to think about, or give it a try. If it doesn't work for you, you've lost nothing." (P25)*

Importantly, this patient emphasised that 'disclosure' must be used appropriately, and OST patients must be offered a menu of options, as opposed to being told that the OST patient must achieve success in exactly the same way as the staff member.

Participants clearly emphasised the importance of increasing the visibility of treatment successes within drug treatment services. However, treatment services may need to promote the visibility of treatment success in a sensitive manner to ensure that OST patients do not feel excluded or inadequate, especially given the findings of low confidence levels of some OST patients.

### **7.2.3 Anxiety of losing medication**

Many OST patients stated that they lived in a constant state of anxiety of losing their medication. This was largely because they did not trust the service to support them in the event that they lapsed:

*Yeah, it's like... I went over to see her [the doctor] yesterday and I was dirty because I had some Saturday/Sunday, and every time I go, I am just worrying, worrying all the way over there on the bus. I've never, ever lied. (P12)*

*I feel all the time that if I have a lapse or something, they're going to end up taking my script or whatever, and it is a constant anxiety. People say there is security in a methadone script but there doesn't feel like there is sometimes, you know. (P36)*

One OST patient explained how he had been given some flexibility because of his mental health issues. However, he remained anxious about losing his medication:

*I think at the minute, I'm having a bit of leeway because of the mental health side of things. But that's ain't gonna go on forever do you know what I mean? It will come a*

*point where... “Well, we can’t help you”, and you’re gonna have to go down some other avenue then.” (P12)*

For some, the fear of losing medication was understood to have contributed to non-attendance at appointments and led to more entrenched use of heroin:

*It's fear of losing their scripts, so they avoid. Once they start avoiding seeing you, then use becomes less easy to reverse, so if they start doing well or they're going off the rails. Yeah, so I think fear of the script being taken. We're in a real juxtaposition as key workers with substitute opiates because there is a consequence. (S12)*

*But a lot of people they do feel, “I’m going to give a dirty sample, they’re going to take me off, they’re going to stop my script or whatever” and ultimately, they just never turn up again and then they go straight back on to the heroin. (P36)*

Some interviewees (patients and staff members) felt that the fear of losing medication contributed to the use of dishonesty and had an adverse impact on trust within the therapeutic relationship:

*So, you come in, and all I’m interested in, or mainly interested in, is not losing my script. So, I will do anything, almost, not to do that. Being dishonest is obviously going to be one of them. So, the whole... I’ve been encouraged to be dishonest, because if I’m honest I’ll lose my script, right? (P10)*

*I think the threat of them losing their script every time they tell the truth because they’ve relapsed isn’t helping them. ..So, they’re not going to be up front and truthful, and the worker’s not going to be able to help them properly because they don’t know the truth, because they’re so scared of losing their script. (P6)*

*Remember, heroin addicts, they’ll do anything for a £10 bag. So, to try and keep a script, people will do all sorts, won’t they? They’ll take the kiddies’ piss in to be clean for a test. All sorts of shenanigans go on. (P6)*

*But then you’ve got the clients who are worried about the impact that if they’re honest, that if they might go and see the doctor it’ll be in the notes that they relapsed, or that they’ve been using. So, we’ve affected the relationship a little bit, the trust. (S9)*

*Like, I had one Friday cultivating cannabis. Now, he’s not going to tell me that. You know? He’s painting the picture of, “No, I don’t go out, I’m not doing anything, I’m staying away from everyone now I’m on a script, blah, blah, blah. No, I’m not up to nothing.” Then it’s like, he’s staying in so much because he needs to water the plants. ... you know what I mean? So, they don’t want you to know because of the consequences of knowing that they aren’t doing what they’re supposed to be, being in treatment and keeping that prescription. (S10)*

However, this use of dishonesty resulted in some cases to stagnation of progress in treatment because it created the illusion that treatment was working when, in fact, it was not:

*That doesn't make for effective counselling if the client is encouraged to be untruthful. (P10)*

*They're thinking they're doing a great job and everything's working, but on the other side of it it's not. They're only having half the story because people are so scared of losing their scripts. (P6)*

The anxiety of losing prescribed medication was a clear *set*-related barrier to achievement of progress in treatment. This fear of losing medication could be related to the practice of discharge from treatment services. The discharge from treatment services could be related to increased risk of overdose when using heroin with substitute medication and the rationale that prescription of substitute medication is not beneficial for OST patients who are not ready to stop their use of heroin (as discussed in Chapter six). Therefore treatment services have to balance the competing needs of provision of security of medication, minimisation of risks of overdose and ensuring that OST patients are benefitting from the prescription of substitute medication.

## **Solutions**

One solution to address the anxiety of losing prescribed medication, was the offer of an unconditional guarantee that patients will not lose their medication regardless of what is said in sessions:

*It's almost like a person centred... a sense of being with that person and allowing them to say how difficult it is to change you know, and say how long they've been injecting and why, and just sort of allowing them to open up about it, and know that if they open up about it that we are not going to take their Script away or criticise them, because in the past sometimes that could happen.....and we just said "we want you to keep the Script, irrespective of what you're doing, because you do need to get through this, and what would your life be like if you weren't on a Script and you didn't have our support?" (S6)*

*Those people need to feel that they're being listened to, they're understood, and no matter what they say they're not going to lose their script over next to nothing. They need to be confident that they're going to get the help, you know? (P6)*

The words “*next to nothing*” suggest that medication should only be taken away in exceptional circumstances. Another OST patient stated that medication should only be taken away in circumstances of diversion or selling of substitute medication:

*If you've got evidence that someone's not selling their script and they're taking it every day, even if they're using on top or doing whatever else, it should never be taken away. If you've got evidence that they're not taking their prescription and diverting it to the illicit market, then yeah, of course, take it away. (P25)*

However, a staff member disagreed and stated that prescribing of substitute medication should be stopped when OST patients are using heroin, because of increased risk of overdose:

*You deal with our clients and it's like “oh well, you know you won't give me my Script, and why are you stopping this now, and why can't I have an increase?” They're just now joined up, and because it's safety, I think about if they continue to use then something is going to happen. But they are so used to using and living in this environment that they don't think they'll ever overdose. (S8)*

The discrepancy between the patient and staff perspectives suggests that treatment providers are faced with meeting the conflicting demands of encouraging honesty (to help support subsequent progression in treatment) and minimising the risk of harm to OST patients. This suggests that treatment services may need to specify the exact circumstances in which the substitute medication will be stopped (i.e. if there is evidence of diversion or misuse). This could help to reduce anxiety of losing medication and improve the treatment experience of OST patients, while simultaneously ensuring the safety of OST patients and others.

#### **7.2.4 Anxiety of disclosure of abuse**

An OST patient stated that during his period of heroin use, his accommodation was used as a venue for using drugs and he was threatened on a regular basis for money by people who used drugs:

*Because I had one person staying in my flat with me. He used to be there every day, and while he was there it just wasn't working. He was using me really, as somewhere to take his drugs and all that. So, I had to go through a lot of that, you know? I had somebody knock on my door for money, wanted £100 of my giro every month, threatening me. (P24)*

However, the anxiety of being seen as a ‘grass’ (*set*) prevented disclosure of abuse to treatment services, which affected openness within the therapeutic relationship and progress in treatment:

*There's some things you can't tell (name of drug agency)...you don't want to tell them, "I've got somebody dealing from my flat," or nothing. ...I don't know, just in case I was a grass, or just in case they get in touch with him or something. I just felt like... (P24)*

*(P24's partner): Worried.*

Therefore, the *set* factor of anxiety meant that treatment services were not fully aware of what was happening in the OST patient's life.

## **Solutions**

It was reported that the fear of disclosing abuse from social relationships affected treatment success. A staff member stated that experienced members of staff have invaluable and in-depth knowledge of connections between OST patients. This knowledge could be highly beneficial in the identification of potential risks such as domestic violence or abuse:

*One of the benefits, I think, of having workers who've been in Newport for a long time is that we know the clients so well. We know the connections. We know who's got an issue with who, and I think that is a benefit... think that then you can also know if there will be a potential safeguarding problem, or if Joe Bloggs doesn't get on with Dave down the road because they fell out 10 years ago over a drug deal gone wrong. We'd know when to worry when certain clients come in together, or if you see a vulnerable street-working girl with a guy who used to be a pimp. You can pick up those problems quicker when you've got experience of a place. (S9)*

The staff member said that this invaluable knowledge of experienced members of staff needs to be shared with new members of staff to improve the likelihood of treatment success for OST patients:

*Because really, the older, experienced members of staff are the ones who are able to pass on knowledge to new staff as well. (S14)*

However, it was noted by one staff member that treatment services have failed to retain good staff members because of the perceived authoritarianism of management. Therefore, more effort must be made to retain members of staff and ensure that they are happy to prevent the loss of this invaluable knowledge:

*I think that staff have had a lot of issues with management, and the way orders have been filtered down... I think we need to put more effort into retaining staff, and identifying staff who aren't happy, and when they're applying for other jobs looking at why and what we can do to get them to stay. (S9)*

### **7.2.5 Adverse Childhood Experiences (ACEs)**

An OST patient stated that he continued to use heroin with prescribed medication because of his traumatic past:

*My past gets to me pretty bad. I think that's why I use, my past. (P17)*

For some OST patients, adverse childhood experiences (ACEs) were associated with an inability to form trusting relationships with others and form new friendships:

*I grew up in a family where, on the outside, it was all rosy. It's a very successful family, it was... Whatever. But they were very disengaged and uninterested parents. In my perception, they shouldn't have had children. So, I suppose, between that and the trust, it's... Yeah, it's really shaped the way I interact with people, and my ability to trust in friendships, in relationships, romantic relationships, which then manifests itself in my inability to cope emotionally...I would actively look for the reason not to trust them. (P25)*

The inability to trust people has important consequences for treatment success. It is problematic in the treatment context as without a strong trusting therapeutic relationship, it will be difficult to disclose personal issues and make progress.

*P: Yes. I trusted him. I really did trust him.*

*SK: That was really important, as well.*

*P: Very, very important. (P21)*

*It's that relationship; you've got to build that relationship for somebody to speak openly to you, because nobody will just come in and say "I've got this problem; I've got that problem." Obviously after you've built that relationship, when somebody thinks I like this person, then I think they would open up and speak to you. (S3)*

One staff member claimed that the development of trust is a sign that the OST patient is likely to succeed in treatment:

*The number of times in the last seven years that people have said to me "I've never said that to anyone before". "I've never shared that with anyone before". The number of times that they've said to me "You're the first person who's ever listened to me", and those are the ones that go on and make changes. (S15)*

A lack of trust within the therapeutic relationship could therefore have a detrimental impact on progress in treatment because trust is a) an indicator of treatment success and b) facilitates openness within the therapeutic relationship. Participants also stated that the history of ACEs resulted in the disruption of development from childhood to adulthood:

*Because when he was three years old his mummy's down Pill, you know, sucking a pipe. Daddy's in jail, and he's screaming, little Johnny's screaming and screaming and screaming, and it's the development arrest, isn't it, that three-year-old. Because he can't scream anymore. No one's listening, like. ...Little Johnny then, fast-forward then about, I don't know, 15 years, and he's 18 and he's coming in to treatment with us, you can't even look at him. He'll stick the head on you, or boot your door across the room, because he's not 18. He's still three, like. (P37, ex-OST patient)*

*You're born with a messy great big pile of string and... depends on what your life does to you, whether or not that knits into a jumper or a great knot. All of that, whether you developed emotionally whether you, you know, knits your brain doesn't it. Hundred billion neurones, each of them a thousand connections, a lot of our service users have got a great knot. They are a great knot. (S2)*

The above quotations suggest that ACEs can result in the stagnation of emotional development. This is because positive childhood experiences are needed for the development of connections between neurones. One implication of this disruption in development is that OST patients with a history of ACEs have limited recovery capital to develop fully. This point is explained in detail by one staff member:

*So, eighty percent of doctors who have a chemical dependence are drug free and in recovery in whichever way you want to evaluate it at five years. It's not their medical degree, it's the fact that you don't get a medical degree if all of those other building blocks were not in place. So, they have got recovery capital and the other group haven't and if you imagine a sliding scale between, the... the anaesthetics doctor who went through a divorce and started abusing drugs and had a bad time in his thirties, versus, the street homeless, recidivist offender who was brought up in the care system and the offspring of an alcohol and heroin dependent person and anyone in between is a sliding scale of prognostic indicator. The marker is... there's going to be a very good prognostic indicator, because the level of their brain disorder, the neural pathways are going to be relatively fresh and there's going to be lots of healthy neural pathways there. (S2)*

One implication of the association between ACEs, stagnation in development and limited recovery capital is that OST patients have to start their treatment journey by going back to the point at which development was disrupted by ACEs:

*There's nothing to rewire onto. They've got to start from scratch. (S2)*

However, it was suggested by some interviewees that treatment services have failed to respond appropriately to ACEs because of the a) short length of treatment that does not allow time to address the needs of OST patients who do not have the neural pathways, and b) busyness of treatment services:

*Have you got lots of childhood sexual abuse or whatever issues? Are you going to benefit from time-limited methadone and lots of intensive support to really change your life around quickly, or is it more realistic to put you on low-threshold prescribing and work with you slowly over time? (P25)*

*But in that half an hour, what can you reasonably do? You'll get in, you'll have a nice bit of chit-chat for 10 minutes, get comfortable, then you might start talking about something, and before you know it you can't even finish the subject. It's time to go, the next client's waiting, kind of thing. That is the primary psychosocial intervention in drug treatment services. (P25)*

The busyness of the treatment service resulted in one OST patient leaving the service, because he perceived that staff had no time to listen to his issues.

*Sometimes people are... It's busy, you know. It is busy. I just gets on my f\*\*\*ing bike, gets my dose and f\*\*\*s off. Just go back home. (P17)*

## **Solutions**

The previous section identified that the association between the inability to trust and ACEs could have a detrimental impact on the therapeutic relationship. This implied that treatment services need to increase trust levels to promote progression in treatment. Participants stated that trust levels could be enhanced by spending more time with OST patients. This increased time with OST patients could also facilitate disclosure and optimise benefits from psychosocial sessions:

*Well, when I first had (XXX) as a worker, I put my trust in her, because obviously I had loads of workers before (XXX). About 10 to 12 workers before (XXX). So, I had to grow a bond with her, and that took about six, seven months, like, altogether, to trust her and to be able to open up and talk to her about my feelings and stuff. (P2)*

*It's having that sense of awareness that everyone is different, and we need to connect in a different way, but you can't do that unless you give them the time to build that relationship and trust. (S19)*

Similarly, Chapter six also identified that increased time spent with the OST patient could help with the identification of factors that could affect achievement of benefits from OST i.e., changing quality of drug. This suggested that increased time spent with the OST patient could help to address multiple barriers such as ACEs and changes in quality of the drug.

However, increased caseloads and the bureaucratic requirements of completing paperwork (both *setting*-related factors) were identified as distractions from the development of trust within the therapeutic relationship:

*There is a lot of therapeutic value in saying to somebody, would you like a cup of tea? I think people don't have time for that anymore, because they've got maybe too high caseloads and too much paperwork. (P32)*

To resolve the barrier of increased paperwork, one staff member suggested that paperwork should be completed either on the computer or paper but not both. This would free up time to spend with patients, which would help to enhance trust levels and facilitate success in treatment:

*For example, one of my bugbears is that we double up; we do everything on the computer, but we also do everything on paper as well. We really ought to be choosing one or the other. (S17)*

It was noted above that ACEs are related with stagnation in development and limited recovery capital. One solution to address this barrier could be the adoption of a trauma informed approach that targets reasons for the challenging behaviour:

*I think services need to be more trauma informed as well. So, if someone presents with challenging behaviour, it's about looking at the reasons for that challenging behaviour. (P32)*

The acknowledgement of ACEs could also improve the treatment experience for OST patients who have had a history of trauma:

*It's just having someone take in to consideration the whole... I don't have to know everything, just this person is suffering with... "She's getting counselling and she needs*

*a little bit of therapy”, even though I’ve been in treatment with (name of drug agency) for three years, my mental health is still not fantastic. I’m still being treated for my mental health. Just take in to account little things. (P35)*

The conveyance of both tolerance and warmth could help with the delivery of a trauma informed approach:

*He’s still three, like....So, you know, we need to be tolerant, don’t we? (P37, ex- OST patient)*

*But what I’m trying to say is, if they know that this person is delicate and she’s doing well, don’t... just be a bit more warmer. (P35)*

The findings suggested that the solution of ‘increased time spent with OST patients could help to address multiple barriers. This highlighted the immense importance of spending time with the OST patient, to aid the prompt identification of barriers that could impede progress in treatment. However factors such as limited finances (Chapter six) and the need to complete paperwork could interfere with spending more time with the OST patient.

### **7.2.6 Mistrust among staff members**

In addition to distrust of treatment services by OST patients, some staff members also questioned, or were mistrustful of, the capacity of some OST patients to achieve positive change. One current OST patient who had previous experience of working in a drug agency stated that it was easy to lose hope with long-term OST patients who had struggled with treatment. This ‘losing hope’ directly affected achievement of benefits from OST because it resulted in some cases in the delivery of the bare minimum of interventions:

*There were that many people that came through the door that I thought didn’t really want to change, you just lose all hope. You think, “Well, you don’t want to change anyway,” so you start doing the bare minimum that’s required by the service. You’re not... Workers... It’s almost like some sort of acceptance that people aren’t going to change. The best we can do is reduce the burden on society, so that typical harm reduction model. (P25)*

*Everything is seen as “they’re doing really well,” but there’s no kind of aspirations I suppose above that. (S14).*

These low aspirations of staff members and the delivery of minimal interventions has meant that there is a significant cohort of patients who are engaged with OST on a long-term basis, but have struggled to achieve benefits from treatment:

*We're complicit with keeping people in treatment for 12 years, no change, you know? No anything. They haven't been able to go on holidays for 12 years because they have to come to us. There's been no change.(P37, ex -OST patient)*

## **Solutions**

To address the barrier of mistrust among staff members and promote progression in treatment, it was suggested by one interviewee that treatment services should incorporate the delivery of a clear, distinctive and ambitious recovery strand:

*But also, very clear recovery pathways, and being a bit more ambitious with clients, then being able to link them in with the right help and support, whatever that may be for that person to get them there. (P25)*

A staff member also agreed and stated that treatment services should introduce a separate strand of treatment for OST patients who are stabilised on substitute medication. This transition to a different strand of treatment could prevent stagnation of progress:

*So I think maybe try and introduce something in between aftercare and active, and so they don't become stagnant in active. You know you could say "this is the stage next, and this is what it means, and what you need to do next."(S4)*

## **7.3 Vulnerability**

Participants stated that OST patients are vulnerable for a variety of reasons such as not eating, offending breakdown in relationships with family members or experience of stigma. These underlying issues often manifest as anger or frustration (*set factors*):

*And when someone is angry and is swearing at you, there's always normally a fear or something underneath that... but when you get someone who's angry, they might not have eaten for a week. They may have been in and out of prison. They might not have been speaking to their mum. (S9)*

*They go to their GP, to the hospital, to the shops, along the street, no matter where they go, and people kind of judge them and look down on them and speak to them in a not very nice way. And they come to us, and we are the only place where they can go, and where they can have a rant really. (S14)*

Another OST patient explained that some OST patients could be vulnerable to the influence of the drug using network within treatment services, particularly in the early stages of recovery. For instance, the offers of heroin or requests to purchase methadone could have resulted in use of heroin even when the OST patient is determined not to use the drug:

*Because you can be stood there, even if you are determined to be clean, you'll go there, and there could be a queue of fifteen people there, and like five of them or maybe more you'll have smoked heroin with at some point in your life because it's such a small place, and that's the hardest thing is staying away from the people that you did it with... here's people... when you walk out they're asking you to buy methadone, you know what I mean?... because you are vulnerable at that point. ... I could probably now go and be with those people and it wouldn't bother me, but back then I wouldn't have stood a chance. (P16)*

This suggested that the *setting* factor of contact with the drug using network within drug treatment services could exacerbate the detrimental impact of vulnerability (*set*) on achievement of progress from OST.

The punitive responses of some staff members (*setting*) to the vulnerability (often characterised by anger and difficulty in controlling emotions) (*set*) of patients meant that in some cases underlying fears and issues were not addressed. This ineffective response by treatment services can be classed as *setting* because it involves the imposition of social sanctions (Zinberg, 1984):

*I think sometimes they have to remember that we're working in an inner-city drugs project with vulnerable people who don't always handle anger very well...I understand that staff have a right to feel safe, but we also have to bear in mind that we're not dealing with your average granny in a little granny home, are we? These are people who react differently to us. There's always a lot going on in their lives. I think we've become a bit too quick to dish out the warning letters, to be honest. (S9)*

The punitive approach was also noted to hinder progress in treatment because it either affected openness with staff members or exacerbated patients' aggressive behaviour:

*Well, I think it makes them feel that they can't always be open or be themselves. I think they end up tiptoeing around services, or they do the opposite and kick off even more, almost to make a little bit of a point. (S9)*

## Solutions

Interviewees suggested that treatment services could address the barrier of emotional immaturity by understanding a) the reasons for vulnerability and b) recognising that those who display signs of vulnerability probably need the most care:

*There's always something behind the anger, and a reason they've thrown a chair across the room or tried to smash a window. (S9)*

*It's so easy to write people off, especially when they come across as being anti-authoritarian or disruptive and things like that. It's so easy then to cut those people out... whether it's recovery classes and things like that, because they are disruptive or they're young and immature and causing issues and problems. It's them type of people that end up getting lost. It's them ones that need the care the most. (P36)*

However, one staff member argued that the inappropriate behaviour of OST patients should be challenged to prepare OST patients for integration with society:

*I will go out of my way to follow treatment protocols and explain that to them, but they don't like what they're hearing so they kick-off, and that's when we get the abuse. And I don't think that's acceptable. I know a lot of people say "oh well, that's our clients," but no, that's not what we're trying to do; we're trying to integrate them back into society as well as get them drug free. (S8)*

Evidently, treatment services have to balance the need to understand the reasons underpinning patients' behaviours with the need to support their life skills and support community integration. The conflict between S9 and S8's perspectives highlights the conflict faced by treatment services in trying to balance the needs of understanding the OST patient and the importance of promoting skills to support community reintegration.

### 7.4 Lack of readiness to change

Another important *set*-related factor that emerged during the interviews was related to the idea of being 'ready to change'. Not being ready to change and stop the use of heroin while engaged with OST can increase the risk of overdose because it means that substitute medication could be used in conjunction with strong batches of heroin (*drug*):

*Because every now and then a strong strain could come through and if you're on say seventy ml of meth and you have a strong bag of gear, you're gone, you know? It's dangerous as well but it doesn't happen regular, often, but it does happen. (P4)*

The stage of 'unreadiness' could also affect the efficiency of psychosocial interventions

because the OST patient is not ready to listen:

*If you're not ready in yourself, you know that it's not going to do no good seeing someone or speaking because you know you're going to go and score anyway. (P9)*

This state of 'unreadiness' could also have an adverse impact on absorption of information in the therapeutic session, which could affect the efficacy of psychosocial sessions and hinder progression in treatment:

*My attitude. It was just me being bloody stubborn and wouldn't want to listen to someone. Even though she was just trying to do the best for me, I just wasn't ready to listen. (P9)*

One OST patient explained that the pressure (*setting*) to stop using heroin during the period of unreadiness could exacerbate the detrimental impact of the *set* barrier of unreadiness and actually increase the use of heroin:

*If they say to me, "You need to give up heroin, you need to give up heroin, you need to give up heroin," keeping on every day, I'm just like "F\*\*\* you, I'll just do it even more. Just leave me to do it in my own time." (P19)*

In criminal justice-based treatment services, those who offend and are dependent on heroin are rapidly prescribed substitute medication regardless of whether or not they are ready to stop their use of heroin (Welsh Government, 2009). This practice (a *setting* factor) has resulted in a cohort of OST patients who have been coerced into treatment but who are not necessarily ready to stop their use of heroin. One staff member questioned the value of this practice on the basis that medication does not stop offending behaviour for those who are not ready to stop their use of heroin:

*There's not many that are coming through criminal justice who really want to address their behaviour and their drug use...And the interesting thing is that criminal justice keeps saying if you give them a Script they'll stop offending. No they don't; they continue to offend. (S8)*

A staff member stated that the benefits of Buprenorphine could be attributed to the OST patient's readiness (*set*) to stop the use of heroin. It is unclear if the readiness (*set*) to stop the use of

heroin preceded the administration of Buvidal or if the compliance of medication associated with Buvidal facilitated readiness to stop the use of heroin:

*SK: Thinking about those two clients you mentioned who've done really well, what was the reason they responded so well to Buvidal do you think?*

*I think they were ready to change. I think they were fed up with what was going on. They were both ends of the spectrum; one had children; one has a little boy, and I think they were ready to change their life. (S9)*

Some OST patients felt that benefitting from treatment was wholly dependent on achieving the appropriate mind-*set* of being ready to change:

*You can have the best treatment service but people won't change, unless they are ready to do so. (P1)*

*I don't think there is no way you could make them ready until they can see in their selves they are ready or they just want to wreck their lives and kill themselves and carry on. (P9)*

*There's only so much support you can give and advice and whatnot, isn't there? Most of it is down to the clients themselves. (P6)*

*Like the work that you, (names of workers), I had (name of nurse), they've all been good with me and everything, but it's not about that, I think it's just about the person and if he wants to stop. (P9)*

*There's only so much you can do with them, isn't it? If they're giving positive tests all the time, they don't want to help themselves. ...I find it's down to them. (P33)*

*There's nobody who can help me unless I want. I want to come off it. (P34)*

*But then ultimately then it's down to the f\*\*\*\*\* person isn't it? It's down to the individual like. (P36)*

*But talking to the others, it could be the best counsellor in the world, but unless they're ready to make those changes then you can't do anything. (S20)*

*You can take a horse to water but you can't make it drink. It's not until they're ready to engage psychologically that there's much point. (S2)*

This raised the important question of why some OST patients access treatment services when they are not ready to stop their use of heroin. An OST patient explained that some people may

not be ready to stop their use of heroin, but they access treatment for other reasons such as the need for stabilisation of lifestyle, support with housing and assistance with difficulties encountered with the criminal justice system/council etc:

*You want help, because you're in dire straits, and you need a script because you're ill all the time and you haven't got the money or whatever, so you go into it believing you want help, and you get your script, but you're not fully committed. You understand what I mean? People do it out of desperation, or because they've got to for police reasons, or council reasons, housing reasons, et cetera, because there's lots of reasons why people go and try and get a script, whether they're really ready for it or not, sort of thing. ...because you're in such a low place you need help from somewhere, and it is a relief, you know, when you have your... You're not constantly ill. So, it is a massive help, but at the same time you're probably so depressed and low you haven't got that motivation and fortitude to keep on, to stay off the gear, and make a massive change in your life, and it is a massive change. (P6)*

P6's quote suggested that at the stage of unreadiness, engagement with treatment services is still beneficial but low motivational levels could be a barrier in stopping the use of heroin.

## **Solutions**

There was strong consensus that patients will not succeed in treatment unless they are ready to change. This begs the question of whether or not patients can be helped to become 'ready to change'. Based on my professional experience as a key worker, I believe that all patients can be motivated to change through the use of motivational interviewing techniques and the evidence supports this view. Indeed, research has shown that "Even for clients with low readiness, motivational interviewing serves as a vital prelude for later therapeutic work" (Centre for Substance Abuse Treatment, 1999; p.39). As explained above, many participants stated that OST patients cannot be helped if they are not ready to stop their use of heroin.

One OST patient stated that he had not initially benefited from the input of staff members. However, in the current treatment episode, he had reflected on what keyworkers had said to him in previous treatment episode, because he is now ready to stop his use of heroin:

*She'd say what I was saying now, but I never used to take it on board back then. But then looking back then and I'd listen and stuff even you said to me before and I wouldn't*

*listen sometimes and I wouldn't, but now like you realise at the last moment kind of thing. (P9)*

One important implication is that past behaviour in treatment is not necessarily an indicator of future behaviour and that staff should be aware of this:

*If I see a name that I recognise I probably will have some sort of opinion, like "oh, so and so again." And I probably will have a feeling that they are probably not going to do well, and I'll probably think that it'll be the same as last time. (S18)*

Participants suggested ways in which OST patients who are not ready to change or stop their use of heroin could be helped. The accumulation of recovery capital for OST patients who are not ready to stop their use of heroin, begs the question of whether treatment services can facilitate conditions that could initiate 'readiness' of the OST patient to stop the use of drugs:

*He's not going to change, but I feel like I've sort of... although I'm a substance misuse worker, I feel like I've helped him positively in the area that he needed to change, and maybe in a couple of years, or maybe when... I don't know; I know he's not going to change now, but he's got more stability in his life now, or hopefully he will because he's been set up with those agencies. Hopefully he'll come back in a couple of years, and he'll be like "yes, it's my time to change now; thank you for what (name of drug agency) has done." (S20)*

The lack of readiness to change and stop their use of heroin raises the important question of how treatment services can optimise the wellbeing of OST patients who are not ready to stop their use of heroin.

Many OST patients and staff members suggested that treatment services should have two strands of treatment based on readiness to change. It was suggested that one strand should focus on purely harm minimisation for OST patients who are not ready to stop their use of heroin, while the other strand of treatment should focus on recovery and abstinence from heroin use:

*Personally, I think services would do quite well to better distinguish those pathways and make it more acceptable for methadone prescribing as a crime-reduction initiative, just to keep people from going into withdrawal and committing desperate crimes. Using on top is perfectly okay. Low-dose prescribing, using on top being perfectly okay. You're not going to get kicked out of treatment no matter how much you use. (P25)*

*So there could be a harm minimisation kind of pathway where we do the harm minimisation stuff, and there's a length of time on a Script where I guess the goal isn't abstinence straight away, and there's some safety measures in, and we can just allow that person to be on the Script for safety measures, or crime reduction, and we work with the service user on "this plan is to keep you safe for now; we can look at recovery a little bit later on, but this for now is to keep you safe while you are using drugs." (S18)*

*It would be a split service, and it would be for people who wanted to actually give up heroin, and people with needs. I don't know; you could go between the services if you wanted to. (S14)*

One patient stressed the importance of differentiating between OST patients based on readiness to stop the use of heroin. According to this approach, prescription of pharmaceutical heroin (rather than other forms of OST) and unstructured harm reduction-based interventions could be given to OST patients who are not ready to stop their use of heroin.

*So the ideal would be maybe someone comes in, says "right, I don't want to give up heroin, but I would like to kind of find safer ways to do it," and we could maybe try pharmaceutical heroin, or something, and they could reduce consumption (S14)*

*If they've got to that point and they're going to do it, you know we've got to make sure that people are using safely. So anyone who's injecting has learnt how to inject off their mate. Nobody's been shown how to inject, nobody knows, but they've done it by either trial and error, or because their mate showed them. So we should be kind of looking at... and I know some people might look at it as encouraging maybe, but we should be teaching people how to do things safely, because if you can teach someone how to inject safely, then you're going to cut down on abscesses. (S14)*

*We can just allow that person to be on the Script for safety measures, or crime reduction, and we work with the service user on "this plan is to keep you safe for now; we can look at recovery a little bit later on, but this for now is to keep you safe while you are using drugs." (S18)*

*Perhaps if we did less structured intervention for those who were more chaotic, perhaps then you can spend more time on other things. (P37)*

Furthermore, the desire to stop the use of free pharmaceutical heroin could be a reliable indicator of readiness to stop the use of both illicit and pharmaceutical heroin:

*You know we're giving them free heroin, so if someone says "I want to stop," then they're really serious aren't they?(S14)*

The use of two strands of treatments is beneficial because it also avoids discharge of OST patients from treatment when they are at their most vulnerable period (e.g., when they have used heroin in response to emotional situations such as bereavement):

*And it could be that the problem is, for instance, they may have had bereavement, and their go-to would be “I’ve had a bereavement, I’m going to use, because this is what I do, and that’s how I cope.” But what we’re going to do then is we’re going to say “oh you’re using, so if you don’t stop using then we’re going to kick you off.” So things are already bad at the moment, so their mental health is bad, they’ve started using again because they’re so upset, and then we’re going to kick them off their Script as well, you know what I mean? (S14)*

The two-tier treatment service could also a) increase the number of positive referrals of OST patients who are ready to stop their use of heroin and b) avoid the use of dishonesty and tampering of urine samples to retain medication, which in turn could have an adverse impact on the openness of the therapeutic relationship (as discussed in Chapter Six):

*You’d be getting positive referrals into the service because you will have people on hand for when they are actually ready to make changes. (S15)*

*Then you’re not getting kicked off your script; you’re not having to take somebody else’s pee in. (P21)*

There was a consensus among interviewees that treatment services cannot help OST patients who are not ready to change, although it was suggested that patients could be supported in becoming ready to change, (e.g. through the accumulation of recovery capital). The main solution offered was the development of two strands of treatment based on whether a patient was ready to change or not. It was felt that this could increase the number of positive referrals, reduce dishonesty and prevent discharge from treatment during periods of increased vulnerability to drug-related harm.

## **7.5 Limited personal responsibility**

One staff member asserted that the early onset of drug use was often associated with perpetration of criminal offences. These delinquent behaviours were linked with a dislike of authority, which was further reinforced by messages from family members that authority figures should be lied to and not trusted. All these factors were understood to preclude the

acceptance of personal responsibility for behaviour and identified as potential barriers to achieving optimal benefits from OST. The absence of personal responsibility meant that OST patients underestimated their role in achievement of success in treatment:

*Often being from a very early age that they've started using the drugs. The drugs have become linked with the crime, and linked with quite a negative attitude towards authority; difficult messages in terms of seeking help. Often their family of origin have sort of had that message "you don't tell the police, professionals; you lie to them." Essentially "you lie to the benefits agency; you lie to the police; you never admit anything." This has been engrained into them from the word 'go', so the true self-awareness, self-regulation, a sense of self-empowerment agency, a belief that "if I change my behaviour, my circumstances will change" is simply lacking. (S2)*

One OST patient agreed with this view and stated that he initially believed that it was the keyworkers' responsibility to 'fix' his/her drug problems:

*First off I thought a care worker would fix me. Having spent years then in and out of clinics, you realise what it's all about and you do actually realise that the only one that can change really is you. (P36)*

This failure to accept responsibility could mean that external factors are blamed for limited progress in treatment:

*So they will often tell you that the reason that they're not doing well is external factors. They will say it was the housing, it was this, it was that, I didn't get the help, I wasn't Scripted. (S2)*

Indeed, the staff member noted that the non-acceptance of responsibility prevented progression in treatment, because OST patients with no personal responsibility often waited for change in others or circumstances, which is unlikely to happen:

*But unless you accept some responsibility, you're powerless to change. So if you think it's all other people's fault, and if you're waiting for the stars to align around you, they never will sadly. (S2)*

The failure to make changes in behaviour but expectation of progress in treatment, could be a barrier to achievement of progress:

*They haven't sort of made any changes, but they're expecting changes and that's why they keep revolving, keep coming round. (S5)*

This failure to accept responsibility was also found to affect the therapeutic relationship due to patients blaming staff for their problems. Indeed, one nurse described a situation where she no longer felt that she could work with a patient who had blamed her for his lack of progress:

*But it's always our fault, because you got me off the Script, so I'm using because of you. I had one who threatened to go and top himself because I reduced him. What? You know what I mean, and that's not funny. And then I find myself justifying why I'm doing my job. (S8)*

Participants stated that the acceptance of responsibility is both empowering and can be the defining moment for progression in treatment. An OST patient explained his defining moment for progression in treatment was the 'acceptance of responsibility' that he needed to look after his parents:

*But if you go "well actually, the reason I'm in this hostel is because I never got a job," or "I never earned any money," they start to see it from... "Well what did I do in this; what's my part in this?" then that's empowering...Yes, often the defining moment is acceptance that "actually, I have a part in this problem you know; I take responsibility for this problem." (S2)*

*"Listen, we're not going to be here forever." I live with them, see, and I was thinking, "Well, they've looked after me all my life. I've been back and forth to jail. They've come to visit me. It's time for me to look after them now." (P13)*

This raises the important question of how treatment services can facilitate the development of 'personal responsibility' and subsequently success in treatment.

## **Solutions**

One staff member stated that the limited surveillance of medication during the COVID-19 pandemic, provided OST patients with an opportunity to exercise responsibility for their medication. For some, this responsibility resulted in improved physical appearance and abstinence from the use of heroin:

*"I don't even have to be supervised." And I think it's also given them a level of responsibility as well, so it's telling them "this is up to you now mate." ..So some of these guys I've been like "here we go; what's going to happen?" and it's them who've sort of turned around, and we've gone "ooh..." and like I said I haven't seen people, and they're the type of people that I need to be bringing in and checking on. And when they do come in they're looking better, and they're giving us clean samples. (S13)*

A former OST patient also suggested that treatment services should provide volunteering opportunities for those who are still using heroin and have limited recovery capital. These volunteering opportunities could enhance personal responsibility, enhance self-worth, increase self-esteem and strengthen motivation to apply for employment:

*So, it's about including people who are still using to come in and do... even if it's making tea in a drop-in, I think we just need to make services a bit more inclusive for those who lack recovery capital. (P32)*

Another OST patient explained that the responsibility that is associated with volunteering helped to improve her self-esteem and motivated her to apply for work in the field of substance use. This is clearly indicative of achievement of success in treatment:

*...and you felt self-worth, where before you just felt like a service user. With recovery, they start giving you responsibilities, and you can climb up the volunteer ladder, which makes me feel good. It makes me feel good sitting down and helping others and showing them different paths that they wouldn't have considered if they hadn't spoken to you. That was really good, and that's what made me want to go into this line of work. (P21)*

This patient's quotation implied that the new identity of 'volunteer' was associated with more self-worth, as opposed to the previous identity of an OST patient. Similarly, the responsibility of volunteering increased self-awareness and also worked as an intervention, which enabled an OST patient to gain benefits from treatment:

*First time I'd ever volunteered, because I'd always been predatory. Take, take, take, take, take. You know? Never given anything in my life, and all of a sudden, I was teaching people to read in a prison setting, and I loved it. ...Well, for me it was a new feeling, wasn't it? It was a buzz. That got the dopamine crackling, you know? So, it was that, and then I started to find out a lot about myself and all the rest of it. I did have other things to give, and I could see that what I was giving was working, and it was also working for me as a therapy. So, then I was doing a detox at the time, from 130ml of methadone. (P37)*

This suggests that provision of trust through volunteering responsibilities or increased responsibility with medication could increase personal responsibility and promote progression in treatment.

## 7.6 Shame

Shame was deemed to be an important factor that could affect achievement of success from OST. The failure to re-enter services following a lapse after a prolonged period of abstinence was linked to fear of disappointing family members and feelings of shame. This shame can be problematic because OST patients are not receiving benefits of treatment services during the period of non-engagement which can in turn lead to entrenchment of the drug-using lifestyle:

*One of the problems we have with some clients is that when they make a mistake, having done really well, they disappear. Because they just can't face us. They feel like they've let us down (S7)*

*It would only have been just before Christmas I signed up. I've been so ashamed to sign up with them. I was ashamed of myself really for taking the drugs in the first place. (P8)*

Interestingly, the strong therapeutic relationships with staff members developed during previous treatment episodes were insufficient to address this barrier of shame. For instance, one OST patient stated that the good therapeutic relationship with the nurse in the previous treatment episode, contributed to a sense of disappointment that he had let her down. These feelings of disappointment made it difficult for P26 to access treatment again:

*I have messed up because she had been so supportive and she had got rid of me, smacked me around the head and said good luck that kind of thing. And here I am again. I felt so terrible. (P26)*

## Solutions

Treatment services could address the barrier of shame of returning to services through the encouragement of strong relationships, but to also emphasise that OST patients are always welcome to return to treatment services if they need to do so (as expressed by a staff member):

*If they ever do relapse, obviously we try and explain that to them "we're here; we're here to support you; even after you've ended treatment, we're still here to support you, and we're only a phone call away," and I think that gives a lot of confidence to them. (S3)*

When interviewed, a doctor involved in the prescription of OST stated that he used sense of humour to address the shame associated with lapses:

*I constantly remind them and then that that they're not letting us down. We're here to help and we are not getting paid by results... I just make it a joke. (S7)*

## **Conclusion**

This chapter has drawn on interviews with staff and patients to identify the *set*-related barriers to achievement of success in treatment. It has also presented solutions to address these barriers as identified by the participants themselves. To summarise, the *set* barriers identified were a) low levels of confidence, b) mistrust of treatment services, c) vulnerability d) lack of readiness to achieve positive change e) limited personal responsibility and f) shame.

In relation to low levels of confidence, interviewees suggested a variety of solutions including acknowledging the difficulty of achieving and maintaining abstinence, the use of visualisation techniques, and empowering patients to take control of their lives. To address the mistrust of treatment services among patients, solutions included: prompt identification of mental health issues, videotaped assessments to ensure consistency of sessions and accountability, the use of role models who have achieved life successes despite histories of entrenched drug use, and more time with the OST patient to build trust. Retention of staff with in depth knowledge of connections between OST patients could also help to address the barrier of mistrust. The main solution for addressing vulnerability of some OST patients was to improve understanding of the reasons for vulnerability. However, there is clearly a need to balance the need for empathy for an OST patient's vulnerability and the need to prepare him/her for integration.

It was widely recognised that patients were unlikely to make progress in treatment unless they were ready to change. However, it was also recognised that getting people ready to change was no easy task. Accumulation of recovery capital and the choice of two strands of treatment based on readiness of the OST patient to stop the use of heroin were identified as ways of helping to address the detrimental impact of unreadiness on achievement of benefits from OST. The limited personal responsibility was linked to failure to be proactive in the achievement of success in treatment. The provision of trust through volunteering opportunities and responsibility with medication could help to address the barrier of limited personal responsibility and promote progression in treatment. The shame of relapse prevented re-entry into treatment services, when support was needed. This could mean that the OST patient is deeply entrenched in the drug using lifestyle and they are not receiving support when needed.

The adoption of the ‘open door approach’ and sense of humour could help to address the barrier of shame and promote progression in treatment.

One important finding is that increased time spent with OST patients could help to address multiple barriers, but limited finances and paperwork could affect implementation of this solution. A promising finding is that the impact of *set* barriers could be alleviated by *setting* solutions (e.g., interventions that focus on accumulation of recovery capital, enhancing visibility of success in treatment, prompt identification of mental health issues and increased time spent with the OST patient). Yet, the findings also suggest that *set* barriers such as lack of readiness cannot be easily addressed by treatment services. Instead, to maximise time resources, OST patients should be offered the choice of two strands of treatment based on their readiness to change. The next chapter will discuss how *setting* barriers could contribute to non-achievement of benefits from OST and the solutions elicited from participants on how these *setting* barriers could be addressed.

## CHAPTER EIGHT - *Setting* related barriers

### Introduction

The previous chapter presented the *set* barriers that could deter the achievement of optimal benefits for the long-term OST population and identified potential solutions that could help to overcome these barriers. In this chapter, the focus is on *setting*-related factors. *Setting* can be described as “the influence of the physical and social setting within which the use occurs” (Zinberg, 1984; p.5). This chapter will explore in further detail the *setting* barriers presented by participants that could prevent achievement of benefits from OST i.e. 1) overemphasis on performance indicators such as abstinence and attendance monitoring 2) aspects of treatment provision (failure to address ACEs, impact of treatment on lifestyle, contact with drug using network, waiting list) 3) aspects of psychosocial interventions and 4) other factors (lack of recovery capital and stigma) that could interfere with optimal achievement of benefits from OST. This chapter will also present solutions that could help to address these barriers and promote progression in treatment.

### 8.1 Overemphasis on performance indicators

In Wales, treatment agencies must meet key performance indicators (KPI) and these KPIs are standardised for all OST patients (Welsh Government, 2021). These “national performance indicators apply to treatment services (delivered in Wales) for individuals who misuse alcohol, drugs and other substances” (Welsh Government, 2021, p.4). Progress of treatment services and KPIs are monitored by Area Planning Boards and the Welsh Government Substance Misuse Advisory Regional Teams (Welsh Government, 2021). The interviews highlighted that the obligation of treatment services to meet KPIs may conflict with the needs of OST patients and subsequently affect achievement of progress in OST. The focus of treatment on certain issues and the neglect of others could contribute to non-achievement of benefits from OST. The focus on stopping heroin use (i.e., abstinence) was a recurring issue.

#### 8.1.1 Abstinence

KPI five emphasised that treatment services must have an “increased number of ‘treatment completed’ closures” (Welsh Government, 2021, p.11). According to the KPI, “treatment completed will be deemed as either problematic substance free or by client reaching treatment

goal(s) as agreed at the commencement of treatment” (Welsh Government 2021, p.10). This suggested that the KPI encourages both the completion of treatment and achievement of abstinence.

This standardised definition of treatment outcomes creates unrealistic targets which are in themselves a barrier because a) it does not acknowledge the characteristics and background of the OST patient and b) abstinence is not an appropriate goal for all OST patients:

*Whereas on the other end of the spectrum, you've got someone who's hugely genetic, all their family have had mental health problems, they were in foster care, they had foetal alcohol issues during pregnancy, during their developmental stage. ..I'm not going to compare the treatment outcomes for the person who had a bereavement or lost their job and went down and had a bad patch so. (S2)*

*We always want people to get squeaky clean. That may not be what's best for them, or is ever going to be right for them, in the context of their lives. (S9)*

*I think expecting them [all OST patients] to be abstinent for a start is unrealistic. (S14)*

The focus on abstinence also facilitates an illusory situation where OST patients are forced to be dishonest about their true motives for entry into treatment and staff members pretend to believe that the OST patient wants to achieve abstinence. Overemphasis on achieving abstinence also results in loss of focus and repeated failure in treatment:

*What tends to happen is that service users, they want a script, they need to say in order to get a script and they need to tell us, "I want to get off drugs". And they tell us what they know we need to hear. We pretend to believe them. And I think that then what happens is that each time it is a failure and that maybe is because of how we're defining failure and success, because of our definition and their failing to meet it, what they learn is, I'm beyond help. (S2)*

This repeated failure to achieve abstinence can in itself become a barrier because it reinforces the message that the OST patient cannot be helped by treatment services.

OST patients stated that the focus on abstinence and subsequent fixation on negative drug test results resulted in treatment services failing to consider the service users' circumstances of use. This failure to consider reasons for use resulted in detoxification from substitute medication and subsequent loss of employment:

*So, you can say, "Okay, three strikes." True, three strikes, but it wasn't an ethically sound decision, is what I'm saying... Well, firstly she... I was mystified at her attitude. It was like she was setting me up for failure. The fact that I was working didn't register. It didn't even seem to be a positive with her. Surely the priority is for me to keep my job. (P10)*

Another OST patient also stated that the fixation on abstinence meant that the reasons for positive drug test results were not considered. The OST patient explained that she had used co-codamol for toothache but had not realised it was an opioid. When she subsequently tested positive for drugs, it was assumed that she had used heroin. The circumstances of extraction of teeth and history of consistent provision of negative test results were not considered. This emphasis on positive drug test results and abstinence resulted in a) immense anxiety of attendance of appointments and b) affected the relationship with staff members:

*I had three of my teeth removed and I didn't even know this, I could not believe it and I was on codeine, Co-codamol for the pain. So, when I went in, it showed up as opiate. ...I begged them to send that urine off to show that it weren't heroin, and do you know what they turned round and said? I'm going to get upset now. This is... It is what it is. "It's going down as a cross." ... So, for them to just dismiss it like they did, it really knocked me off my perch a little bit. I think I was in bed for about four days. I couldn't even get out of bed... See... look I'm talking about this, this is how worked up I am about going on Monday...From that point on, the relationship had gone then. I'd got no trust for the nurse who I had been seeing every three weeks. (S33)*

Despite the strong focus on abstinence, a staff member stated that treatment services were not good at empowering OST patients to achieve abstinence from drugs:

*This probably goes to what's not working well, but I don't think we're helping people get off drugs. (S18)*

The staff member elaborated and said that the preoccupation with achievement of abstinence resulted in dishonesty. This implied that the 'preoccupation with abstinence' did not help OST patients to stop the use of drugs:

*because sometimes you're so fixated on that negative test, and you forget, and I've done it myself and forget everything that might be going on around that client, and I think that sort of makes the client feel they need to be dishonest, and bring in false tests or avoid appointments. (S18)*

Therefore, the overemphasis on achievement of abstinence facilitated dishonesty. This dishonesty could have an adverse impact on the therapeutic relationship because it affects the openness in therapeutic relationship, which is needed for progress in treatment:

*I want you to be able to feel that you can tell me anything, because at the end of the day we're not going to progress until we're on the same page. (S11)*

The detrimental impact of this focus on abstinence is further exacerbated by the fact that this has to be achieved within a specified time period (i.e., treatment services have an obligation to report to the area planning board on progress as measured by KPIs) (Welsh Government, 2021). Time-limited treatment is classed as *setting* because it is related to “rules of conduct” (Zinberg, 1984; p.5). In the 90s drug policies mainly focussed on retention in OST and reduction of drug-related harms. Recently there has been increased focus on successful treatment exits and abstinence from drugs. While harm reduction remains at the heart of Welsh drug policies, interpretations of the recovery model as involving ‘abstinence from drugs’ and the KPI ‘completion of treatment’ suggest that there is an increased focus on detoxification from OST (Neale et al. 2013).

At the drug agency, there are no time limits to the prescribing of substitute medication within generic services. However participants stated that they were actively encouraged to reduce their use of substitute medication within generic drug treatment services, and long term maintenance on substitute medication was no longer encouraged:

*The minute we signed up for this, you know, with the commissioners, with the (name of drug agency), and the days of maintenance are gone, it became a time-allotted treatment. (P37)*

*But over now in (name of drug agency) they've got this new policy where there's no maintenance, you do have to get off like you know. (P31)*

*They [drug treatment service] haven't got the money to keep you on it. I understand that. The place I'm going to have, GSSMS. They can keep you on it for basically as long as you want. (P34)*

However this active encouragement of all OST patients to reduce substitute medication could be a barrier to achievement of treatment success, because there is insufficient time for treatment

services to address complex issues such as sexual abuse, homelessness and long history of drug use.

*Have you got loads of health and social-related crime complications in your life? Have you been extremely destructive? Have you got lots of childhood sexual abuse or whatever issues? Are you going to benefit from time-limited methadone and lots of intensive support to really change your life around quickly, or is it more realistic to put you on low-threshold prescribing and work with you slowly over time? (P25)*

*“We’re not even going to allow you to stay in treatment for long enough to make these good changes”. ...So, it’s contrary to what the evidence suggests and then what we see is increased drug related deaths, increased numbers of people going into prisons, increased problems with homelessness. (S2)*

OST patients involved with the IRIS (the criminal justice component of the drug agency) are prescribed substitute medication for a period of six months before they can be transferred to generic community-based prescribing services. However, OST patients are faced with uncertainty of what happens at the end of the criminal justice treatment programme (IRIS) because there is no guarantee that all IRIS patients will be transferred to the mainstream service.

An OST patient explained that the expectation of achievement of abstinence within the six months in IRIS was unrealistic, especially given that he had a history of prolonged use of drugs:

*I have been addicted to opiates all of my life... most of it....So for somebody to turn around and say to me we want you clean in 24 weeks ... ha it is not going to happen. (P5)*

The unrealistic expectations of providing negative urine samples within a short period in the IRIS programme affected the emotional wellbeing of OST patients because it created anxiety and placed immense pressure on them:

*Now I don’t want to tell you, but listen we haven’t got time now. You have got to start or otherwise you are going to be off treatment... wow! Now my anxiety levels are through the roof... whoomph! I walk out through the door and go f\*\*k it! (P5)*

*I’ve only just got up to my ceiling dose, what am I like... fourth month, and then it’s the pressure of “oh my God,” I’ve got basically no time now. (P31)*

## **Solutions**

As explained earlier, there is no time limit within generic services. However recently, drug

treatment services have encouraged the reduction of substitute medication. This encouragement was deemed to be counterproductive because there was insufficient time to address complex issues (as explained in earlier section). However, some participants agreed with the reduction of substitute medication because it increased the availability of spaces for new OST patients who want to change their use of heroin:

*People who have been on it for 20 years or whatever, or a long time, they should be knocked off, because it's not fair on people who are trying to get help. It took me three years altogether to get help, it did. (P2)*

*I think that's fair to everybody then, because somebody on the waiting list is desperate to change, you know what I mean, and we're stopping them because we've got all these long-termers who don't want to move. (S9)*

However, the solution of long-term maintenance of substitute treatment, without the encouragement of substitute medication is not feasible because of limited funding resources:

*I don't think we can pick up the tab for long-term maintenance; I don't think there's funding for that. (S8)*

An OST patient also questioned the efficacy of long-term maintenance of substitute medication with no planned end, because it is a form of enabling and the prescription of methadone is only a harm reduction tool that should be used to help OST patients achieve success in treatment:

*I'd never, ever looked at methadone as anything other than a harm-reduction tool. I'd never, ever, and I'd been on 130ml of meth. I'd never, ever looked at it as anything other than a harm-reduction tool, to keep somebody alive, to give your next-door neighbours a break so you don't have to burgle their houses, so you can get up in the morning without that craving. (P37)*

To resolve the *setting* barrier of limited finances, OST patients who want long-term maintenance could be referred to community-based (rather than service-based) GPs. However, this solution is problematic too, because doctors do not all have the expertise or inclination to work with people who use drugs:

*I think that maybe they should go back to GPs, but then there lies the problem; they don't know how to cope with them. (S8)*

One patient asserted that in order to truly move forward in treatment, OST patients should be detoxed and empowered to lead lives that are independent of treatment services:

*I think we should be detoxing them, and I know it sounds bad, but almost making them...  
“You know you can’t be with us forever; you have a responsibility to change your life.  
(S8)*

However, this solution of rapid detoxification in itself does not address the barriers of complex issues related with long histories of drug use and fear of reduction of substitute medication. The findings suggest that a slow-paced and OST patient-controlled reduction is important because it could reduce the risk of relapse and the intensity of withdrawal symptoms at lower doses. It was noted that appropriate support from peers or a designated worker could help with reduction of medication and successful cessation of medication within the time period:

*I can come down in smaller amounts if I want to. I don’t have to come down. (P3)*

*I want to go slower now because the lower you go, you do feel it because you’re not having the same as you used to have. (P24)*

*Well, it’s good to come down a bit because I’ve been on it for so long, but I don’t want to come down off it too quick where I’m going to relapse. (P33)*

*I think about trying to quell the nonsense rumours about how bad it is coming off the last doses of methadone... They listen to people in their peer groups rather than listening to professional workers. (S10)*

*Like somebody sat in [treatment service], somebody sat up here, somebody sat in [treatment service] for that specific reason, tapering off meds. (P21)*

However, the findings suggest that reduction of substitute medication might still be difficult for some OST patients who have been prescribed medication for long periods of time and who have achieved success in other areas of their life such as employment, family and cessation of offending behaviour etc:

*...there should be some provision for people who have been in this for such a long time and who want to be on methadone and feel that they cannot... for such a long time and you haven’t used for fifteen years and you’ve got family, you’ve got a job, if I put myself*

*in that position, I'd be like, "No, I'm keeping this. I don't want to give that up. I believe that that's the only thing that's keeping me in this good place. (S16)*

*Methadone helps me from going back down that bad road again. ...It's... I haven't got to go out... I'm working now, I'm putting money in my pocket. I haven't got to go out to steal to buy heroin or anything, because that's where I would always turn to in the end, when I started taking heroin, is stealing to pay for my habit. .. I'm more or less normal except for the methadone. (P33)*

There is no time limit for the prescription of substitute medication within generic services. However, participants stated that generic services have recently started to encourage OST patients to reduce their substitute medication. There were mixed perspectives on whether this encouragement to reduce medication is beneficial or not. Some participants felt that long term prescription of medication was needed to address complex issues. However, some participants expressed concerns that prescription of substitute medication with no planned ending is not financially feasible and enabled the stagnation of progress in treatment. Various options of support with reduction of substitute medication were discussed but the issue remained of whether all OST patients are capable of successful reduction of substitute medication.

### **8.1.2 Attendance monitoring**

The Welsh Government (2021) emphasised the importance of attendance of appointments. For instance, KPI one stated that treatment services must “(I)ncrease the number of clients who engage with services between assessment and planned ending of treatment, by reducing the incidences of clients who do not attend (DNA) or respond to follow up contact post assessment date” (Welsh Government, 2021, p.5). However, some participants stated that the focus of treatment services on attendance of appointments, could affect achievement of success in OST.

For instance, some participants noted that non-attending OST patients may be making better progress than those who do attend:

*Then is it better, to have a client that attended all their appointments and filled in all their bubble gram charts, or a client who's stopped taking drugs and has got a drug and is, living a normal life? I think attendance of appointments, although it can be useful, is not a marker for recovering and actually. (S2)*

*If somebody's got a job and are working and they're constantly busy, then it's different, and they just want to come in, have their appointment, and they want to get back to family life etcetera. (S3)*

*The reality of it is that if somebody is clearly not interested in, I don't know, the psychosocial type of work but is sticking to their script and not using heroin it would make very little sense to evict them out of treatment. (S7)*

The main implication is that attendance alone is not a good measure of treatment success. Indeed, another staff member stated that mandatory attendance of appointments does not equate to meaningful engagement with sessions:

*...if the motivation for attending the appointment was, I won't get my medicine unless I come for my appointment, was that meaningful engagement right or actually, does the engagement mean more if it's a choice that the client's made because they decide that they want to do the psychological work (S2)*

Non-attendance of psychosocial appointments was linked by some staff to patients' lack of interest in the topics covered:

*The key worker, well he never turned up for my appointments, but I don't find your appointments interesting. (S7)*

This non-attendance means that they will not make progress in treatment, as OST patients are not receiving the benefit of psychosocial sessions. Therefore for some OST patients, non-attendance is a good sign of achievement of success in treatment (such as employment, family life) but for others it could be a sign of not achieving benefits from OST.

Failure to give importance to attendance of appointments could indirectly affect the morale of psychosocial keyworkers, which in itself can be a barrier and affect the efficacy of psychosocial sessions.

*And because it's a snub the system, or doctor has not taken it seriously and is almost giving a green light to the client to say "the key worker's not very important." ...To me that's quite an important concept as well because if you've got a key worker that's demoralised and doesn't feel that he or she is doing is worthwhile that causes problems as well. (S7)*

This raised that important question of how treatment services encourage OST patients who are 'not benefitting from treatment' to attend appointments.

## **Solutions**

Few solutions were offered by participants to address the barrier of non-attendance but an important one, was that the onus should be on treatment services to provide relevant, interesting and individualised sessions that meet the needs of OST patients, which would increase the likelihood of attendance and progression in treatment:

*There must be very talented key workers who can, who know how to draw up a curriculum and a programme that keeps up people's interests and it tailors to their needs (S7).*

### **8.1.3 Inability to attend appointments**

Another important point is that some OST patients may be willing to attend but they may be unable to do so for various reasons beyond their control. Homelessness, for example, may make it difficult for OST patients to attend appointments because they are torn between the obligations of attendance and rushing back to make sure that their tent is secure:

*When they're engaging with ourselves, they're probably thinking "hold on, if I don't hurry up and have my methadone, and don't hurry up back to my tent," or "if I don't hurry up back to where I'm supposed to be staying, somebody could damage it, somebody could break it down," so you know, that's the way it is. (S3)*

Furthermore, some OST patients may genuinely forget to attend appointments and have difficulties with the cost of transport, which could in turn result in discharge from treatment:

*I know a lot of people say they forget their appointments, but I do generally believe that some service users do forget their appointments, and they haven't got enough money for the bus, and sometimes these people don't always fit into the bracket of what (name of drug agency) is asking for (S4)*

*well, she did have me struck off for a day because I didn't turn up for appointments. ..Now, I always like my appointments sent in the post because I knew... because I have got a really terrible memory. (P14)*

Therefore, sometimes OST patients are discharged from treatment for reasons beyond their control. This discharge could obstruct progression in treatment because OST patients are not receiving psychosocial interventions or substitute medication during the discharge period.

## **Solutions**

One important finding was that assertive outreach and flexible informal support could address

the barrier of discharge of treatment for reasons that may be beyond the control of the OST patient:

*I would ask them what time would suit them. Actually, I'd go to them. So, if they were living in Mission Court because they were homeless, I'd probably... I think we don't... there's no such thing as hard to reach; we just don't have good enough access....It's asking honest questions. "what time do you think you might get up? And then what? Go and score? How long will that take you? Where have you got to go? What about if we meet in such and such a place at three o'clock?".(P32)*

This suggests that treatment services must meet the needs of OST patients, as opposed to OST patients meeting the obligations of treatment services.

## **8.2 Treatment provision and delivery**

The Orange Guidelines stipulated that the provision of OST involves the prescription of substitute medication, delivery of psychosocial interventions, care planning, drug testing, identification of general healthcare needs, responding to impact of trauma on OST patients and provision of support with aftercare (Department of Health, 2017). Participants raised some interesting points relating to the context of treatment and its delivery, which could affect achievement of benefits from OST.

### **8.2.1 Focus on the importance of medication**

Historically, treatment agencies focussed on the importance of substitute medication as a miraculous life changing form of treatment:

*Sometimes at the beginning we thought methadone was the be all and end all. It was this amazing thing that was going to change people's lives. And it does. It's a brilliant thing. (S16)*

However, not everyone succeeds on methadone. Indeed, one staff member noted that one OST patient consistently increased his methadone but was experiencing no benefits from treatment:

*But yes, you do get a lot, but "I need to increase my methadone" is not enough for me...And he's injecting in his hands, using on top but I don't think things are ever going to change for him. (S20)*

Similarly, the focus on medication (rather than being proactive in achievement of success in

treatment) was found to reinforce the unrealistic belief that it is a “magic wand” that will solve all problems and reduce emphasis on the need for personal responsibility to make progression in treatment. This reduced personal responsibility was in some cases noted to result in reluctance to work towards achievement of progress, which in turn affected achievement of benefits from OST:

*You know, “Oh, I’ve taken my methadone, oh I’m good.” It doesn’t work like that. You’ve got to work at it on your part. (P14)*

*They don’t really want to do the other work. They just want to get on the script. And sometimes you can’t break through that one sometimes. (S1)*

Furthermore, the emphasis on the significance of substitute medication was reported to contribute to low levels of self-efficacy (*set*) because the OST patient attributed success to the medication, as opposed to their own determination and hard work:

*They don’t recognise that methadone is a tiny part. They’ve done the hard work. I will always tell them, “You’ve done... Methadone is such a small part. You decided to stop using. You made all of these changes.” That sometimes doesn’t necessarily click. (S16)*

This low self-efficacy could in turn impede progression in treatment because it strengthens the belief that they are incapable of achievement of success in treatment:

*I guess it’s because they have never been able to achieve that belief within themselves that they can get off that once and for all and be totally truly drug free. (S15)*

## **Solutions**

A staff member reported that one way of reducing the importance of medication in the treatment process would be to encourage OST patients to reduce their use of heroin prior to starting on a substitute medication (*setting*):

*But the guy who’s waiting, when we had the lockdown and was in prison, he’s gone down from four to one [bags of heroin] you have to do some of that work before you can get a script. (S6)*

It was also noted that exploration of non-medical options could help to reduce the importance of substitute medication and promote progression in treatment:

*Yeah, because (OST patient's brother) who does the... he weaned themselves off heroin, didn't he? With counselling and that kind of thing. (P14)*

*I don't think everybody who is on heroin necessarily needs a script always. (S6)*

An OST patient explained that his keyworker suggested that the non-medication option of breathing exercises will help with stopping the use of heroin. However, he stated that he needed medication to help to stop the use of the drug:

*she was saying to me that I could give up heroin by doing breathing programmes, and I'm like "I'm sorry but you just can't; if it was that easy I'd have given it up a long time ago." (P16)*

It is unclear if P16's belief that 'breathing exercises' will not work has been facilitated by the overemphasis on medication by treatment services or if the prescription of substitute medication is the only suitable treatment option for this OST patient.

An OST patient explained that the busyness of employment (*setting*) helped her to reduce the perceived importance of substitute medication. She explained that the busyness contributed to the mindset (*set*) that she did not need the medication:

*I even ran down to work one day and I completely forgot to take my meds. I forgot to take it, and I was like... I started sweating, I could feel myself starting to get prickly skin and started to sweat and everything, and then all of a sudden it just clicked, and it was like "I've forgotten to take it." But I stayed there, I finished my shift, and after that it was like "hang on a minute, I don't really need it. (P27)*

An OST patient suggested that treatment services should try to provide activities, particularly for OST patients who may have limited structure in their lives:

*There should be more things for people to do to keep them busy... Lets go and have a weekend off. Let's be busy. Let's do some adventures. Just do something. (P5)*

The above solutions suggested that treatment services need to be more proactive in the exploration of treatment options that does not involve prescription of substitute medication.

### **8.2.2 Failure to address ACEs**

Chapter seven discussed the fact that a significant proportion of OST patients had a history of ACEs, which prevented them from achieving positive outcomes from treatment. The fear surrounding the handling of ACEs meant that in some cases disclosures were not addressed and just entered onto the system as a case note:

*All we do is, that staff member goes in to handover with other members of staff, and says, "Oh my God, I just heard a terrible story from so and so in their assessment about some really bad childhood abuse". Then that's it. It goes on our data system as a note and that's it. (P32, ex OST patient)*

The absence of appropriate skills of staff to address ACEs also meant that disclosures were addressed inappropriately:

*I've seen a lot of people delivering sessions like that, right, and not being able to put the worms back in. Then I question them. I think, "Hang on a minute," you know? (S?)*

*They say that's okay. That's just... You know, practice my CBT. F\*\*\*ing how dare you, like? (P37)*

Inappropriate work with ACEs by non-qualified staff was viewed as dangerous as it could have serious negative consequences for the patient and their family members:

*Then somebody then has got to pick up the blinking pieces then, which is more likely, the poor woman that he's going to go home to and bash the f\*\*\*ing living daylight out of, you know, because he's caught up in that spiral of this or that or whatever. (P37)*

Both perspectives highlight the important point that staff members felt underqualified to respond appropriately when ACEs are disclosed. These ineffective responses to ACEs could initiate the revolving door where OST patients are cycling in and out of treatment services, without gaining any benefits from treatment:

*I think if we don't start to look at the wider needs in terms of childhood trauma, access to counselling, they will continue on that revolving door, and not make treatment gains. (P32)*

Referrals to external sources of support could also mean that OST patients are subjected to numerous assessments. This could affect the emotional wellbeing of OST patients, because OST patients are forced to relive the trauma numerous times:

*So, they've got to talk about those traumas again and again and again and it makes them relive the trauma. (P32, ex OST patient)*

The OST patient elaborated and stated that this reliving of the trauma could result in frustration. The OST patient gave an example where repetitive questioning by mobile service providers or the bank could cause irritation. Furthermore, the frustration is magnified for OST patients possibly, because of emotions that are often associated with trauma:

*It is hard. If I had to repeat the same information every week to a different person, I'd be shouting and screaming saying, "I told someone this". When we ring... I don't know, when you ring your mobile phone provider or your bank and they ask you the same questions, "what's your security number", we get rankled by it. I do. I'm like, "I've just answered this". Yes, it's the same for them and we're not dealing with trauma. (P32)*

## **Solutions**

An ex-OST patient stated that drug treatment services do not have the necessary funding to offer intensive support that addresses ACEs. Therefore, treatment services should refer OST patients who are not benefitting from treatment to residential rehabilitation for intensive support:

*We don't have the budget to provide more intensive support. So, for people that are not making any treatment gains, I'm a massive advocate and believer in tier four. I think residential treatment options are the gold standard. (P32)*

Another solution offered was for drug agencies to work with external sources of support at a multi-agency site and introduce the adoption of a common assessment form. This could mean that both financial and time sources are maximised, and OST patients do not have to re-experience their traumatisation:

*I think services need to be co-located. (P32)*

However, the cautious approach of treatment services in the avoidance of risks, could prevent the co-location of treatment services:

*So, there's barriers all the time., information sharing protocols that never get signed or agreed, that are sat there ten years later. People are just a bit... I don't know if they're risk averse... (P32)*

The solution of residential rehabilitation for OST patients who are not gaining benefits from treatment underlined the importance of the adoption of an individualised approach that reviewed if OST patients were gaining benefits from treatment.

### **8.2.3 Negative impact of treatment rules/regulations OST patients' lives**

Many OST patients were complimentary of the treatment, support and aftercare that they had received at the drug agency:

*And Kaleidoscope were still there for me, they were still ringing to see how I was getting on, because you know, you still have that little bit of support afterwards with them. Yeah, it was brilliant. (P8)*

*Couldn't have done it without (name of drug agency). (P15)*

Despite these compliments, staff members stated that treatment services were not perfect and could only offer limited freedom to OST patients. This limited freedom was identified as a barrier to success because daily (or at best, weekly) attendance for pick-ups, prevented OST patients from doing other activities:

*I mean the best they're ever going to get from us with regards to freedom and methadone treatment is once a week collections; that's the best they're going to get from us. They'll never get more than that. (S13)*

*But sometimes it is like a ball and chain (P26).*

These restrictions on freedom whilst in treatment were described as interfering with family life, preventing the planning of spontaneous holidays, affecting dignity and perpetuating stigma:

*You tried to hide it, but you've got to go to the chemist. If you're invited up to stay with your family for a few days, and you say, "No, I can't." They go, "Why?" You've just got to come up with some stupid excuse. Just lie. (P29)*

*You don't want to be like me when you are 50, go to appointments and ask for permission to go on holidays and stuff. (P26)*

*If you wanted to go for a daytrip or... Well, anywhere really. If you wanted to go somewhere, you've always got to pick your methadone up before you can... (P33)*

*Because all of that self-labelling of, I'm a person on a medication that's highly stigmatised. You know, I have to go in every day, or I have to take it every day, there's a self-labelling which is negative and of course, one of the drivers for addiction is negative mood and negative self-identity. (S2)*

Treatment services are legally obliged to manage the risk of patients transporting high quantities of Class A medication. Inevitably, these obligations were noted to be in conflict with the OST patient's ability to take sufficient medication on holidays:

*We generally as a rule don't do that because of the risks associated of someone taking three weeks' worth of methadone in their hand luggage, or you know they could lose it, or someone could get hold of it. (S13)*

Additionally, the interference of treatment with holidays was described as more pronounced for OST patients who travelled abroad for long periods of time (e.g. to visit family members living in other countries). The long duration could potentially mean that these OST patients missed appointments and was subsequently discharged. Secondly, OST patients could be left in a situation where they have to use heroin because of insufficient medication and unavailability of medication in holiday destination. This could result in OST patients returning to the use of heroin after prolonged success in treatment:

*Yes, and after two weeks, obviously if they're going to stay for a month and a half and they've only got two weeks of medication, when they come back they are going to be out of treatment. So you've worked really, really hard with a client for about two years, and then after he decides to go to Pakistan, and he's only got two weeks of medication, and he's staying in Pakistan for four weeks; what is he going to do for the next two weeks when he has no medication? Firstly, he's going to be out of treatment, because he's going to miss frequent appointments that take place, and secondly, he's not going to be able to find methadone anywhere, so he'll have to go back onto using substances. So, the work you've done with him for about two years has just gone down the drain. (S3)*

In many respects, holiday trips and visits to family members can be considered as progress in treatment. However, the rules surrounding consumption and transportation of medication were noted to potentially reverse the progress achieved by the OST patient.

More worryingly, OST was noted to interfere with patients' employment situation and prospects. Two problems were noted including the timing of clinics which meant patients working nightshifts had no time to sleep and recover, and the health and safety rules preventing certain types of work if the worker is taking opioids:

*So it's affecting their working life, that they are working a nightshift and then coming straight to (name of drug agency), collect their medication, they have an appointment with me, whereas typically they'd be going to sleep and recovering for the work in the night. (S20)*

*I can't get a job because of probation and the fact that I am in treatment. You know... I got to declare this because of health and safety and all the rest of it. You know there is lots of things around all this that is never talked about. (P5)*

## **Solutions**

Treatment services are tasked with avoiding the risk of harm while at the same time promoting the autonomy of the OST patient. The challenge is a difficult one but has been helped by the introduction of Buvidal. Buvidal is a prolonged release solution of buprenorphine in a pre-filled syringe (Datapharm, 2020). It is administered as "a weekly or monthly subcutaneous injection by a healthcare professional" (NICE, 2019; p.6). The injection method means that the OST patient has greater flexibility to go on holidays and visit family members without worrying about carrying medications or official letters to explain the reasons for transporting Class A medication:

*If they got Buvidal, and I inject them with Buvidal, obviously depending on how long that will last in their actual body, if it'll last for a month then great, we've got no worries, they know they don't have to carry no bottles with them, they don't have to worry about taking letters with them explaining what the medications are for when they get stopped, so I think it's really, really good. (S3)*

Another advantage is that the risks of misuse and diversion are removed through the injection of substitute medication:

*Now when you give someone an injection into their arm, you can say, categorically, I have removed those risks. Because it can't come out of their arm. (S2)*

However, it was recognised that Buvidal was not the perfect solution. Indeed, some staff members noted that the administration of Buvidal removes regular contact with the pharmacy and this could mean that non-drug related risks of OST patients are not monitored:

*Yes, and also it can influence their drug use, you know homeless, domestic violence; they turn to drink and drugs to be able to cope; it's a coping mechanism. So I think you're able to manage their risk a bit better if you've got other agencies like pharmacists on board. (S4)*

Another staff member agreed and stated that the prescription for Buvidal is not suitable for chaotic OST patients. The staff member explained that prescription of Buvidal had resulted in her OST patient disengaging from the treatment service:

*I'm not so sure about giving it to chaotic, risky, vulnerable people...I've got a very chaotic client who was put on Buvidal at the start of lockdown who's still using on top, and because we're not seeing her regularly it's harder to maintain contact with her, because she now knows she's only got to turn up once a month. So, it's allowed for a certain level of disengagement from service. (S9)*

However, the same participant also stated that Buvidal could be appropriate for some chaotic OST patients in circumstances of domestic violence. For instance, the administration of Buvidal could ensure a) compliance with medication and b) avoid circumstances in which the perpetrator of domestic violence prevented the OST patient from consuming substitute medication:

*Well, my one client had domestic violence and couldn't always attend her doses because of the violence, or the partner would prevent her from coming in for dosing, so from that point of view ...it ensures compliance with a script. (S9)*

Buvidal is clearly beneficial in resolving the conflict between the monitoring of drug related risks and promotion of autonomy of OST patients. However, there were concerns that the monthly administration of Buvidal could preclude the monitoring of non-drug related risks. The mixed views surrounding the suitability of Buvidal for chaotic OST patients suggested that treatment services must carefully consider the circumstances, needs of OST patients and non-drug related risks, prior to the prescription of Buvidal.

#### **8.2.4 Contact with drug using network**

The regular encounters with drug-using networks at both the pharmacy and drug agency meant that OST patients were often faced with the temptation to use heroin. Several patients noted the difficulties associated with this:

*You are still seeing every single person that you used heroin with every day, so you ain't got a chance. (P16)*

*It only takes the one person to say, "Oh, coming for a smoke?" It's that mentality, it's in there. Yeah. It's like Jesus leading you towards it, because everybody follows. "Oh yeah, they've got a good batch there - oh, I'll just go." (P11's girlfriend)*

*You go in to that little back room, you take your medication and then you come out and they start talking to you and that's it. It's that downward spiral again. "Do you want to meet up? I'll get some stuff" and that temptation, when it's there in front of you, if you're not strong enough which I weren't, you're going to get back down that path. (P35)*

*So, every time you go to the clinic and you see the crack dealer and all your mates going "I've got some really good gear" how on earth are you going to expect someone to give up drugs in that environment? It's like giving someone who is an alcoholic a prescription that they have to pick up from the pub every day. (S2)*

These regular encounters also mean that OST patients are faced with pressure of peers asking where can heroin be purchased or pressure to sell their medication:

*But they keep on, "where can I get some heroin" and they rip your ear off. "I don't know, where do you usually go? What are you asking me for" (P12)*

*They try to buy your medication off you...None of that helps, like. (P24)*

One patient explained that this kind of pressure led to him being discharged from treatment and thus stopped him from achieving positive outcomes:

*I struggled with that, because now and again I needed a tenner for a bag, and I was caught once, and they stopped my medication and all that because of people like that. (P24)*

Paradoxically, these findings suggest that the treatment system that is intended to promote progression in treatment, is in itself a barrier to the achievement of success through facilitation of contact with drug-using networks.

## **Solutions**

One patient suggested that seeing OST patients on a one-to-one basis (as was the case during the COVID-19 pandemic) would help to limit contact with the drug-using networks:

*The thing is, at the moment, because of the COVID, it's all one-to-one. One in and then one out. One in, one out. Before that it was loads of other peoples used to go in. I didn't like it when it was like that because that's when you bump into a lot of other people. (P13)*

The monthly administration of Buvidal (*drug*) also meant that OST patients had less contact with their drug-using networks. For one patient, being on Buvidal reduced his contact with services, which meant that he was no longer involved in activities that had a detrimental impact on his mental health:

*...it just stops me going out and bothering with other people, and then doing certain things and getting in trouble and doing all those things and that. (P13)*

### **8.2.5 Waiting list**

Many OST patients reported that they experienced *setting*-related barriers even before the prescription of medication. One patient described that he waited seven months for the prescription of medication:

*So, I did refer myself in April and then in November they put me on methadone so I waited seven months and it was the longest seven months of my life. (P15)*

This waiting period for medication is classed as *setting* barrier because it is part of how the system operates. It relates to the problem of limited resources that prevent some individuals from accessing the treatment they need and want (Mui et al. 2014). Recently the Healthcare Inspectorate Wales (HIW; 2018) identified concerns by staff members that the waiting period for substitute medication is too long in Wales. Similarly, between January and March 2020, there were 64 people waiting for substitute medication at the drug agency (Drug agency, 2020). This long waiting list was attributed to COVID-19 restrictions as well as the retention of long-term OST patients in treatment, which limited the availability of new treatment spaces (Drug agency, 2020).

The waiting period for substitute medication was noted to affect the wellbeing of OST patients because it was associated with suicidal feelings and extreme financial struggles. These financial difficulties meant that one OST patient had no money for food or electricity:

*Many a time I'd be sat here, I'd be ill and I just wanted to end my life because I was so ill and I had no friends or family I couldn't go and borrow ten pound off to go and get a bag and all my benefit money was going on gear, so I used to sit in the dark, go weeks without food because my money used to go all on gear. (P15)*

Therefore, the absence of a supportive network (*setting*) exacerbated the difficulty of waiting for medication. However, the waiting list had a negative impact on OST patients with supportive networks too because it placed financial pressure on loved ones to fund their use of heroin:

*Like I say, my dad, I was like, "well I'm getting back into treatment and he can see the end then, and I promise you it really will end", but like I say every day was money, money, money. I needed at least thirty quid a day off him and he used to give it to me and like I say he'd stop paying certain bills and that, just to see me through. (P4)*

The waiting list also resulted in further entrenchment of drug use and perpetration of offences to fund the use of heroin:

*They're so far into it they can't turn their life around. (P38)*

*But I've had to offend because I've had no methadone. (P22)*

*I would think any worker worth their salt, would understand that that person not yet in treatment had to commit crime. (P37)*

It was noted by one staff member that treatment services determine the access to substitute medication, based on attendance of appointments. However, some OST patients are disadvantaged because they are unable to attend appointments because of their chaotic lifestyle:

*SK: Are they making [treatment services] decisions [on access to substitute medication] based on paperwork, or Palbase?*

*Yeah, and they've attended every appointment. But like I said to you, these are vulnerable chaotic people. Some live in tents. They're not going to turn up to every appointment. They physically can't manage that. That is an unfair expectation. So, that is a huge barrier, I think. (S9)*

Some staff members felt that the open-ended nature of the waiting list strengthened the preoccupation with medication and resulted in no meaningful engagement in psychosocial sessions:

*So it's about the key workers keeping them engaged, which I'm sure is a really, really difficult thing to do when people can't see any light at the end of the tunnel, you know what I mean? (S14)*

*We're meant to keep in contact with clients every week to assess their motivation and keep them engaged, but try ringing someone every week who's desperate for help. It's really difficult to have that conversation, and they end up getting a bit ratty, like, "Why are you ringing me? I'm waiting for treatment." It's really difficult to have those conversations all the time. (S9)*

One staff member was concerned that the limited transparency of waiting lists affected the efficacy of psychosocial sessions and could be a trigger for increased use of heroin:

*... well you can't really give a time estimate, but it's going to get more and more every week, but they're getting knocked by it. They're going to be upset about it, and they might even increase. (S20)*

Participants stated that motivation to change is strongest when people approach treatment services and declines with time on the waiting list. Delays could therefore result in lower levels of motivation by the time they reach the top of the list and affect subsequent achievement of benefits from OST:

*The biggest motivation you will have is on the day that you make that referral for yourself, or somebody refers you. You get tired. You get worn down by it all. The moment has passed. It's passed. It's passed. (P37)*

*And are we really catching people at the peak of their motivation, ...but a lot of the time people have been waiting months and months, and I wonder if their motivation is absolutely exhausted by that time. (S18)*

The long waiting list encouraged some OST patients who are not ready to stop their use of heroin, to lie about their progress rather than lose their place to someone who may be more ready to engage and change. One staff member speculated that this dishonesty could in turn affect achievement of benefits from OST because honesty is needed for success in treatment:

*And I think then, the knock-on effects are that people know how difficult it is to get on a Script, which means that actually, when they're not in a place to use the Script properly, ...they use on top, and then they're lying about it, and they're being quite sort of deceptive about what's going on in their lives. (S14)*

## Solutions

There was strong consensus among participants that rapid access to medication would be beneficial and even help to save lives:

*Rapid access. That. Now, that in itself would solve so many problems. (P37)*

*That would save a hell of a lot of lives, that would. Getting people on a script quicker and earlier. (P38)*

*I would love to see people prescribed from day one, because that's when they are motivated. (S10)*

It was felt that rapid access to substitute medication could eliminate the concerns around the waiting period and promote progress in treatment instead:

*Just bring somebody in, do your initial assessment, test them immediately for opiates, and then give out the Script the following week, and then you can do the work; then you can do the important work which is to change their thinking about substances, to open up opportunities for them to change their lifestyle et cetera. That's what we should be doing, not worried about where they are on the waiting list. (S11)*

A staff member elaborated and stated that the access to rapid prescribing must be delivered in conjunction with interventions that targeted homelessness to facilitate conditions that allowed for attendance of appointments and progression in treatment:

*But also getting the OST, the prescription access, to coincide with that housing and that removing them from that cycle of homelessness, begging, looking for their next bag, their next fix, not being able to keep a script, not being able to keep appointments, all of that stuff. (S2)*

However, some staff members felt that there should be a preparation period, prior to access to rapid prescribing. This preparation period is needed for the assessment of whether OST patients are ready to stop their use of heroin or not. The staff member stated that the preparatory period would also ensure that OST patients valued their medication:

*Otherwise, it would be like give up now, sort your head out or next time you won't be on a programme that quickly...That should shock people into things because it's hard enough to get on a programme now for them to stay on a programme so if someone's not capable of doing that then they really don't care. (S10)*

*But I do think if we had unlimited treatment spaces I would still look at the two to three appointments kind of rule...they need to show that they are motivated to change, and they need to show that they're willing and able to engage in the treatment plan. (S18)*

*Don't be too quick to give them a Script, because that's the downfall; they just think that's the magic pill. I think we should have more funding, more key workers to work with these people, and then have discussions, around the table discussions about "are they ready to come into treatment?" If you don't, and if you don't work with your colleagues, they come in to get a Script, and then you don't bloody see them, and then I've got the problem then of trying to chase them. (S8)*

Interestingly, none of the OST patients stated that a preparation period was needed prior to prescription of medication. This could be because some staff members are unable to fully empathise with the pain of withdrawal felt during the waiting period.

*Yes, it doesn't matter how you relieve it, you just want to relieve that pain, and you want to be normal. (S3)*

### **8.3 Psychosocial interventions**

Psychosocial interventions are described as interventions that strive to facilitate changes in psychological and social states (Department of Health, 2017). Given that psychosocial interventions are an integral part of OST, this section will focus on the barriers involved in the delivery of psychosocial sessions that could affect the wellbeing of the OST patient (Department of Health, 2017).

#### **8.3.1 The worker**

Some OST patients perceived that the absence of lived experience can be a barrier because the pain of withdrawal and issues faced by people who use heroin are not understood. This perceived lack of understanding resulted in a power imbalance between the OST patient and staff members:

*Because what I find, and what I hear a lot of, is people just say when they go to their sessions, "They're preaching to me and they haven't got a f\*\*\*ing clue what they're on about. They haven't been there and done it, they don't understand." (P6)*

*Well, you've got all this power over me, sitting preaching to me, and you don't know what I'm on about or what you're on about." (P5)*

Some OST patients perceived 'lived experience', as beneficial for a variety of reasons such as increased empathy and enhanced ability to spot signs of manipulation:

*But where it's somebody who's been there and done it, they know what to say to you. They understand where you're coming from. I always felt better with somebody with more experience. If I sit down with somebody with more experience, I always felt more positive than I did with somebody who hasn't then. (P4)*

*You know, they say relating one junkie to another? (P38)*

*You can empathise with the person, and you can sympathise with the person as well. (P27)*

*That you can trust and you know that they understand what your struggle was like. (P21)*

*Because they want to keep them on side, especially if they're using. They want to try and manipulate them in some way. "I want to up my meth," or... Do you know what I mean? They start working on them. That's another thing see. They can't see that sometimes. I can spot that a mile off. (P21).*

A staff member stated that his lack of experience with drugs was initially a barrier to development of rapport with OST patients:

*I personally, because a few people ask me about my drug or my alcohol background, I will be honest I have never had a problem with it, and therefore all of a sudden my lack of experience in that field if you like is invalidated, it invalidates the whole process. We go into the "You don't know what I am going through." (S15)*

However, support from staff with lived experience was also found to affect progress in treatment, because of risk of contagion relapse and romanticisation of heroin use:

*I would say the only difficulty with things like the peer mentoring scheme is that obviously, peer mentoring scheme is full of service users or ex-service users. So I've kind of seen if somebody is relapsing, they'll take a load of them with them, you know what I mean? (S14)*

*I also feel that sometimes people who have been ex-drug users in the past are not always the best people to talk to, because I think sometimes, when people have been through something and come out the other end, sometimes they only remember the good parts of it. (S14)*

A staff member also stated that recruitment of staff with no lived experience was important because it allowed OST patients to distance themselves from heroin and at the same time enabled staff members to learn about heroin:

*And they're not going to learn always like, they will never be free of heroin if all they ever do is talk with people that have done that...I'm not going to learn unless I talk to them. (S12)*

An OST patient also explained that recruitment of staff with no lived experience was also beneficial because they enjoyed talking to someone who had no experience of drugs but had positive qualities of being 'understanding' and 'sympathetic':

*You may know somebody who's on the same level like in that as well, and they understand you. Rather than another heroin addict sort of thing. Somebody who knows about it but is not smoking it but is sort of sympathetic as well. It's nice to have that. (P28)*

## **Solutions**

There were varied perspectives on whether lived experience or absence of lived experience affected the achievement of benefits from OST. The conflicting perspectives on whether treatment services needed to employ staff with lived experience or no lived experience highlights the importance of the adoption of an individualised approach, that matches the specific needs of OST patients:

*Because we all have different skills so it is looking at which person may be best for them, which key worker could fit with them and that we say, "Yes, they are going to have a good relationship." (S9)*

An OST patient also stated that staff with no 'lived experience' could improve their skills by working with OST patients with a diverse range of dependencies. This could help staff with no experience of drug use to gain a better understanding of the issues faced by OST patients:

*They need to deal with lots of people with lots of different varying degrees of addiction, and just get a gist of how it all works. As to what you would do for them, there's no better training than listening to addicts every day, you know? (P6)*

### 8.3.2 Interventions

The content and style of delivery of interventions was also deemed to affect the achievement of success from OST. Patient-centred formal interventions with open ended questions were deemed to be unhelpful in progression of treatment for some OST patients:

*So what do you think you can do better next time? They are asking me how to do it. Excuse me, I have come to you for help ... Don't ask me. I am asking you. (P5)*

This suggests that some OST patients need more directive interventions. This assertion surprised me as it conflicted directly with my strong belief in the efficacy of motivational interviewing and that everyone could be empowered to find the answers within themselves.

This perception of lack of directiveness in interventions resonated with other participants who felt that the absence of planned endings could impede progress in treatment. For instance, a staff member stated that none of her OST patients had planned exits from treatment:

*I haven't had one planned exit with any heroin users, only alcohol; not heroin. (S4)*

The absence of planned exits in treatment could further waste valuable time resources, particularly for OST patients who have achieved abstinence from heroin for long periods for time:

*Do they really need to check-in anymore; can I realistically do anymore for that person who hasn't used for six months, or twelve months? (S6)*

This absence of planned exits for people who use heroin was partially attributed to institutionalisation of treatment services:

*we have a little bit of institutionalisation, which I'm not saying is a bad thing, because people feel very supported by (name of drug agency), but it's the clients who say, "I'm off to collect my juice." So, then they become institutionalised to the service. (S9)*

The absence of planned exits was also attributed to retention of OST patients because of the mistaken belief by staff members that OST patients still needed treatment, when in reality

they did not. Furthermore, it was easy to get into the practice of retaining OST patients when treatment was no longer needed:

*And sometimes we don't think it's done; maybe sometimes we think people are still dependent on us or something. Hopefully I don't do that too much, but I think it's so easy to slip into that isn't it; it's so easy to just give people one more session. (S6)*

This absence of planned exits could prevent achievement of success in treatment, because it strengthens the 'revolving door' where OST patients are cycling in and out of treatment services, without making any gains from treatment:

*it's scary for everyone, it's scary for parents, but actually, you do need to do it, because otherwise you're going to end up with a child who's never going to leave your house, they're never going, you're going to be paying the bills forever. So it's the same, as we'll end up with a load of service users who never want to leave our service, and are constantly coming in and out, in and out, in and out, and we're providing medication for them over and over and over again. (S14)*

In fact, participants highlighted the importance of planned exits for the achievement of success in treatment:

*I definitely think as well, letting people go at the end in some way, you know at the end of their treatment. (S14)*

*You know you can't be with us forever; you have a responsibility to change your life. We're all in charge of our own destiny, and we've helped you up to here, now you've got to step off and fly." (S8)*

A staff member stated that exits from treatment are needed for dissociation from the drug using identity:

*I think they need that real break, that break away to just go "actually, this is who I am now, but in the future I might like to help people," you know what I mean? But to have that break away completely, just so they can actually discover who they are, so they don't always have to be that kind of drug user, or ex-drug user. (S14)*

In fact, a staff member defined success in treatment as independence from treatment services:

*They're no longer on drugs and they don't need to see us anymore. I think it would be a success if that person is not on drugs, has a new life where they are not dependent, and they are contributing to society. (S19)*

This raised the important question of how treatment services could help OST patients in a planned and structured way.

## **Solutions**

The view that open ended interventions do not work for some OST patients highlights the importance of adopting an individualised approach that considers the varying emotional needs and different requirements of support:

*What works for me isn't necessarily going to work for Fred down the road. It has to be... I think it has to be much more individualised. (P25)*

*Oh... I'd say treat everybody as an individual really; it's not one treatment suits everybody; everybody is different and everybody has all different needs, and emotional support is needed differently as well. (P27)*

The above section identified that the absence of planned exits could have a detrimental impact on achievement of progress from OST. The use of regular reviews could be a useful tool for identification of signs that the OST patients is no longer benefitting from treatment:

*So I would maybe look at having regular reviews of how things are going. I know we're doing that right now, I know that's happening right now, but I sort of wonder whether like after maybe a year in treatment, or eighteen months in treatment, whether you have to have some sort of review, and maybe an end point that you have a Script for... (S6)*

The emphasis on the importance of planned exits by participants suggested that treatment services may need to incorporate long term goals at the assessment stage itself.

## **8.4 Other factors**

This section will address other *setting* factors that are not directly related to treatment but could affect achievement of benefits from OST.

### **8.4.1 Lack of recovery capital**

For some participants, achieving abstinence was not enough as long as they lacked recovery capital, such as structure in day and positive social friendships with non-drug using network:

*When you stop using drugs, your mind's unoccupied. Your life's unoccupied. It's just this massive void. (P25)*

*It's like if you're sat down having a cup of coffee with somebody, and they start talking about their past and stuff, and if I brought up something from my past, because my past has all been around drugs, so if I brought up something like that they'd be just like "oh you're a drug addict; you're a junky," so it's a bit hard; I do find it quite hard to socialise with normal people. (P27)*

*because I'm in temporary accommodation it's quite boring. I can't stay out overnight or anything because I've got to be there every night, and because I don't know anybody in the block that well, the block of flats I'm in, it's a bit of a... yeah, I get really bored. There's only so much daytime TV you can watch. (P27)*

*Now when you take all those elements away, you've got an individual that suddenly has nobody to socialise with because all his usual social circle, he or she needs to stay away from, because that's a trigger for drug use. Then, all the motivation that they used to have on a daily basis is gone. And not taking drugs anymore, I'm not doing that; now what do I do? (S11)*

*I do honestly believe that actually, when they kind of take a breath and come out of that, to go from that madness to kind of like "okay, what am I doing with my life now?" It's hard; it must be really hard. (S14)*

*Yes, there's nothing to replace it, and that in itself, what do people do? And then we wonder why people have mental health problems, or then they relapse, because they've got nothing in place to replace it. (S14)*

The above quotes suggested that abstinence from drugs in itself does not equate to achievement of success in treatment. As seen from above, the anxiety (*set*) of stigmatising responses to disclosures of use of drugs could prevent the formation of new friendships (*setting*).

## **Solutions**

Both staff members and OST patients stated that treatment services should provide exciting activities such as taster courses that promote integration to target the emptiness of the abstinent lifestyle and promote progression in treatment:

*I think they should be doing things like in the universities and the college, taster courses, really short kind of bursts of different subjects, so that people can spend a day doing history, or like having an overview of different things, or art, or Tauopathy, you know what I mean? Just so people can go and think "Oh I really enjoyed that, and I would like to explore doing that a bit more," you know what I mean? (S14)*

*Lets do something. Lets do something. Lets go and have a weekend off. Lets be busy.  
Lets do some adventures. Just do something. (P5)*

The achievement of abstinence might be particularly difficult for OST patients who have limited recovery capital or who do not have a supportive network may also struggle with achievement of success in treatment. For these groups of OST patients, treatment services could offer a) activities that enhance recovery capital and b) provide opportunities for reintegration (e.g., taster courses in Universities and colleges). As mentioned in the methodology chapter, I visited the Hot Dog morning at the Basement in Newport as part of the ‘microethnography’. At the Hot Dog morning, I witnessed OST patients reaffirm encourage each other to visit the gym in an informal and relaxed manner. This is a good example of treatment services could continue to enhance ‘recovery capital’.

#### **8.4.2 Stigma**

Several OST patients stated that they experienced stigma regularly and had not been given opportunities to succeed in life:

*“Oh they’re junkies...” do you know what I mean? They don’t want to give you a second chance. (P11)*

*But no one’s willing to give me a chance because of my criminal record. I’m a prolific offender, I’ve got 89 convictions. (P22)*

A staff member noted that most of the activities provided within treatment services involve people who use drugs. This has meant that OST patients are not offered opportunities to socialise with people who do not use drugs. This absence of opportunities could mean that the barrier of stigma is not addressed, because reintegration is needed to address discrimination:

*I mean obviously we have diverting activities, and (name of staff) is fantastic, and they do some amazing things, but equally, that is all around, not all of it, but a lot of it is with other service users.... It’s not about getting people out of the setting altogether. (S14)*

*Because if that person then, if one person goes out and they work in a company, and then they disclose to their colleagues “well actually, I used to do heroin,” then hopefully they go “well that’s not what I imagined a heroin user to be,” you know what I mean, and then hopefully the stigma around it becomes less of a thing. (P14)*

This failure to provide opportunities for reintegration could be because staff members could be anxious that OST patients will face discrimination in mainstream society:

*I think it's to do with stigma, and how they're abused by people in society. And yes, you wouldn't want to put someone's child out to be treated in a negative way by putting them in the community; you wouldn't want to do that. (S14)*

The staff member further stated that this lack of integration has resulted in congregation of people who use drugs and further strengthened the stigma that people who use heroin are anti-social, which could in turn affect achievement of benefits:

*We're keeping them close to protect them, but actually we're making things worse, because what happens is they all congregate in one area, they're altogether, and then they're seen as antisocial and a nuisance and all the rest of it. (S14)*

## **Solutions**

Some interviewees suggested that treatment services should provide opportunities for reintegration with people who do not use heroin. This could help to remove the stigma against people who use heroin and provide opportunities for OST patients to move forward in treatment:

*And I think maybe things like getting service users into the volunteer posts maybe, in things which have nothing to do with drugs or alcohol, and kind of getting them into other settings, just so they can kind of trial things, so they can go and see what a carpenter does, or they can go and see what it would be like working on a building site, or gardening, or you know, anything that is just kind of a little bit like work experience. You know like when they go on work experience in school, you know when they go for a week or so, just so people can go "oh yes, I'd really like to do that," or "dear God, no, I'm not doing that." (S14)*

Stigma clearly affected the lives of OST patients in many ways. However, the findings suggested that treatment services can address stigma through provision of opportunities that promote reintegration. This finding is consistent with the earlier discussion that movement away from treatment agencies is needed for the formation of non-drug using identities and achievement of recovery.

## **Conclusion**

This chapter aimed to present a) *setting* barriers that could influence the achievement of benefits from OST and b) solutions that could help to overcome the detrimental influence of these factors and promote progression in treatment. Broadly speaking, this chapter focussed on how the *setting* barriers of focus of treatment services (overemphasis on performance indicators, abstinence and attendance monitoring), aspects of treatment provision (focus on the importance of medication, failure to address ACEs, negative impact of treatment rules/regulations OST patients' lives, contact with drug using network and waiting list) and other factors (lack of recovery capital and stigma) could contribute to non-achievement of success in OST.

The undue emphasis on abstinence is problematic because it results in dishonesty and failure to consider circumstances of use which could have an adverse impact on the therapeutic relationship. Attendance may not be a reliable indicator of success in treatment for all OST patients. In fact, findings suggested that the requirement of attendance while in treatment and waiting for substitute medication could create unfair expectations for those who are unable to attend appointments i.e., homeless individuals. Provision of interesting sessions and assertive outreach could reduce the detrimental impact of non-attendance and discharge from treatment services

The undue focus on medication could have a detrimental impact on self-efficacy and the proactiveness of OST patients to accept their role in the achievement of treatment success. This barrier could be addressed through reduction of heroin prior to prescription of medication, exploration of non-medical options and provision of activities that could enhance the 'busyness' of the OST patient's life. The findings suggested that some members of staff do not have the necessary skills to address ACEs, which in turn could impede progress in treatment. Similarly in Chapter six the remit of the treatment of general health needs by specialist doctors within substance misuse treatment services was unclear. This raised the important issue of whether substance misuse should address complex issues or if these needs should be met by external services. More clarity is needed where and how OST patients can access different forms of support. The issue is further complicated by the finding that time limited treatment is insufficient to address entrenched issues associated with long term drug

use. The discussion also raised the important issue of whether all OST patients are capable of reduction of substitute medication, despite provision of support with reduction.

Treatment also interfered with the quality of life of OST patients and ‘forced contact’ with the drug using network. Buprenorphine helped to address these risks to a certain extent but the administration of Buprenorphine was related with concerns that non-drug related risks may not be monitored. The waiting period for substitute medication was associated with detriments to the emotional wellbeing and finances of both OST patients and their families. There were conflicting perspectives on whether a preparatory period was needed before to prescription of substitute medication. However, the efficacy of the preparatory period was questioned by the finding that withdrawal symptoms affected the efficacy of psychosocial session. The external factors of stigma and the void of abstinence could be addressed through provision of opportunities of reintegration and activities that enhanced recovery capital.

The findings underscored the significance of the adoption of an **individualised** approach. For instance, the conflicting perspectives of the value of lived experience and the possible link between non-attendance and irrelevant sessions highlighted the importance of the adoption of the individualised approach. The mixed perspectives surrounding the suitability of Buprenorphine for chaotic OST patients also underlined the importance of the adoption of an individualised approach. Staff members must know the needs of the OST patient well for the adoption of a truly individualised approach. However, increased workload, dishonesty and focus on paperwork could prevent staff members in getting to know the OST patient very well.

The findings emphasised the importance of reintegration. The provision of reintegration opportunities by treatment services could help to address stigma by challenging the stereotype of people who use heroin and help to develop a positive social network (deemed to be essential for the achievement of success in treatment). Integration could also pave the way for planned exits, which could in turn increase the availability of new spaces and reduce the detrimental impact of the waiting list. The next chapter will discuss how the findings presented in the *drug, set* and *setting* barriers chapters relate to the literature that explores the a) barriers faced by the

long-term OST population and b) ways in which the wellbeing of the long-term OST population can be improved.

## CHAPTER NINE - Discussion

### Introduction

This thesis has presented findings from a qualitative study that has sought to identify ways of improving the health and social outcomes of people struggling to benefit from long-term opioid substitute treatment (OST). In this chapter, the findings from interviews with staff and patients are discussed in light of previous research. The aim is to establish if and how the findings align with or differ from the existing evidence base. In so doing, the chapter highlights the new and original contribution to knowledge that this study has generated.

To help put the research in context, the chapter will begin with a brief summary of the need for the research and a reminder of the research questions. This will then be followed by an overview of the underpinning theoretical framework that was used to help understand the findings (i.e., Zinberg's (1984) *drug, set and setting* framework). Consistent with the thesis as a whole, the findings will then be reviewed using Zinberg's (1984) framework as a structure for the discussion.

### Context

In the UK there is widespread recognition that there is a cohort of long-term ageing OST patients with complex mental and physical health issues that are struggling to achieve benefits from OST (Advisory Council on Drug Misuse, 2019). However, research has shown the achievement of poor outcomes within the long-term OST population is not confined to older people and the ageing process (Metrebrian et al. 2015).

The existing evidence base sheds little light on why some members of the long-term OST population struggle to benefit from OST. Little is also known about how the problems can be solved and what can be done to improve the health and social outcomes of those who have been in OST for long periods without benefiting fully. There is a particular dearth of knowledge about the barriers faced by OST patients and the possible solutions in Wales, as previous UK-based research has focused on England (Notley et al., 2013). This is an important omission given that England and Wales have different substance misuse policies, practices and funding

arrangements. Therefore, what works in England, may not work in Wales, and vice versa. This thesis is focussed on the improvement of health and wellbeing of the long term OST population in Wales. It is therefore directly relevant to the Wellbeing of Future Generations (Wales) Act 2015 which strives to improve the a) social, cultural and economic wellbeing of Wales and b) achievement of wellbeing goals such as a healthier Wales, a more equal Wales, a Wales of cohesive communities and a prosperous Wales.

The limited amount of research that has examined the issues from the perspective of staff involved in the delivery of OST is also a notable omission. They may have a different understanding of the barriers and a better appreciation of how solutions might be implemented in practice.

Most research has focussed on the exploration of barriers within the long-term OST population has focussed on OST patients who have been engaged with OST for five years or more on a continuous basis (Notley et al. 2013; Notley et al. 2015; Moran et al. 2018). This means that there is limited research on long-term OST patients who have been engaged with OST on an intermittent basis. The inclusion of patients who have been engaged with long term OST on an intermittent basis is important, because of the increased risk of overdose at the termination of treatment episodes (Prenoxad Injection, 2019). Most research on barriers in relation to the long-term OST population has focused on OST patients who are prescribed methadone. There is relatively little research that has focused on the barriers faced by the long-term buprenorphine population. This is relevant because of the varying effects of substitute medication and different methods of diversion that are possible with the different forms of OST.

This thesis aims to make an original contribution to knowledge by filling these important gaps in knowledge. An OST patient (with previous experience of working within OST) in the study aptly stated that it is “*impossible to set a set of organisational policies that are going to work for 1000 chaotic drug users*”. This quotation illustrates the huge task faced by treatment services in meeting the individual and specific needs of each OST patient within drug treatment services.

## ***Research aims and methods***

The research questions that this study sought to answer were:

- 1) What are the barriers faced by the long-term OST population that prevent them from achieving benefits from this type of treatment?
- 2) How do these barriers prevent the long-term OST population from achieving benefits from OST?
- 3) What are the solutions to overcome the barriers (faced by the long-term population) that prevent achievement of benefits from OST?
- 4) How can treatment services address these barriers to improve the health and wellbeing of the OST patient?

Qualitative research methods have been used frequently in the substance misuse field to investigate topics related to substance misuse such as overdose, initiation of drug use, the impact of heroin on peer networks and the association between heroin treatment services and drug-related deaths (Ataints et al. 2020; Khozbi et al. 2009; Best, Manning and Strang, 2007; Dennis, 2019). The qualitative approach is beneficial for obtaining detailed accounts of memorable experiences that are personal and relevant to participants' lives (such as key barriers to treatment success) (Khozbi et al. 2009). Therefore, qualitative data were gathered through semi-structured interviews with 38 long-term OST patients who were currently (or had recently) been on OST on a continuous or intermittent basis for a period of five years or more. Qualitative data were also collected through interviews with 20 staff members with direct experience of working with the long-term OST population as well as a 'microethnography' conducted in the sites of the drug agency in South Wales.

### ***Zinberg's (1984) drug, set and setting theoretical framework***

To help structure the findings and to assist in their interpretation, Zinberg's (1984) *drug, set, and setting* framework was applied. This framework has been used successfully in previous drug-related research including studies investigating overdose incidents with populations of opioid injecting women, responses to heroin overdose by people who use heroin, and the efficacy of interventions targeted at sniffing petrol (Atiantis et al. 2020; Lamonica, Boeri and Turner, 2021; Richert, 2015; Lau et al. 2015; MaClean and D'Abbs, 2002). Furthermore, the

Scottish Drug Forum (2020) recently recommended the use of the ‘*drug, set and setting*’ approach in helping to improve understanding of drug use. To the best of my knowledge, while the *drug, set* and *setting* approach has been used to guide research focusing on heroin-using populations, it has not specifically been used with the OST population.

Zinberg (1984) stated that each of the *drug, set and setting* factors must be considered to fully understand the consumption of drugs. Therefore, each of the *drug, set and setting* barriers were examined to enhance understanding of why some OST patients struggle to achieve success from treatment. Zinberg and Harding (1979) emphasised that the *drug, set* and *setting* factors can interact in complex ways. Therefore, in this chapter I will consider how they operate independently of one another but also how they interact to affect the progress of patients in OST.

To briefly recap, *drug* variables can be described as the pharmacological effects of the drug and “pharmacological aspects of the experience” (Zinberg, 1984; Zinberg 1984 as cited in Lau et al. 2015, p.2; Richert, 2015; Mui et al.2014). Frequency of drug use, method of administration, potency, quantities, and purity can all be categorised as *drug* variables because they are associated with the pharmacological effects of the drug (Zinberg, 1984; Ataiants et al.2020; Shewan et al. 2000). The methods of obtaining the drug, different forms of the drug and effects of polydrug use have also been described as *drug* (Shewan et al. 2000; Lau et al. 2015; Lamonica et al. 2021).

*Set* is defined as “the attitude of the person at the time of use” (Zinberg, 1984, p.5). Personal characteristics (age, gender, social class, employment) and personality attributes (impulsivity, curiosity etc) can also be categorised as *set* (Mui et al. 2014). Psychological factors such as previous experiences of using drugs, mood, motives for using drugs, and expectations of the person who use drugs can also be described as *set* (Jansen,1997; Lau et al., 2015, Mui et al., 2014). Negative life experiences (e.g. histories of abuse, losing custody of children), emotional trauma and emotional states of mind have been described as *set* as well (Lamonica et al. 2021, p.7).

*Setting* can be described as “the influence of the physical and social setting within which the use occurs” (Zinberg, 1984, p.5). Physical setting is described as “the place, people and things *present* during the time of use” (Mui et al. 2014, p.238; Lamonica et al. 2021). The change in physical setting such as leaving treatment or prison release can be described as *setting* (Lamonica et al. 2021). The social setting is the group of other people present when use occurs (including the group’s broader values and beliefs) and social relationships with others (Mui et al. 2014).

The remainder of this chapter will discuss the barriers to success faced by OST patients using the *drug, set, and setting* framework to structure the discussion (Zinberg, 1984). The findings will be scrutinized carefully to see how they align with, differ from and add to, the existing evidence base.

## **9.1 Drug barriers**

The interviews with staff and patients revealed several barriers to treatment success that could be classed as *drug*-related within Zinberg’s framework. These included: problems associated with withdrawal during the process of titration and stabilisation on OST, the effects of Buprenorphine medication, the need to self-medicate, the search for pleasure, and the quality of heroin available in the local area.

### **9.1.1 Withdrawal**

When heroin is used for a prolonged period and suddenly stopped, unpleasant withdrawal symptoms may occur, which often leads to continued consumption of heroin (US National Library of Medicine, 2019). Many OST patients stated that they experienced withdrawal symptoms during the titration phase. Some OST patients continued to experience withdrawal even after stabilisation of substitute medication. This is because certain types of substitute medication are associated with fluctuations between withdrawal and stability. This occurrence of withdrawal during the titration phase and after stabilisation of medication affected achievement of benefits from OST. For instance, OST patients reported that the withdrawal was associated with cramps, disturbed sleep patterns, increased likelihood of use of heroin, low

levels of motivation and increased vulnerability to the influence of the drug using network. May et al's (2019) study of nonmedical prescription use in Wales showed that OST patients also used illicit gabapentin, pregabalin and benzodiazepines (in addition to heroin) during the titration phase to strengthen the effects of methadone. The use of the illicit drugs could further enhance the harm to the OST patient because the pharmacological quality and strength of illicit benzodiazepines are not controlled by regulations (May et al. 2019). The use of gabapentin, pregabalin and benzodiazepines with illicit heroin could also increase the risk of poly-drug toxicity and respiratory depression (May et al. 2019).

This raised the important question of how the barrier of withdrawal could be addressed to improve the wellbeing of the OST patient. Many OST patients in my study said that their general health practitioner was reluctant to prescribe pain relief medication to OST patients because they felt that they could not be trusted. This finding resonated with Mistral and Velleman's (2001) survey of general practitioners in Wiltshire. Mistral and Velleman (2001) found that general practitioners (GP) reported drug patients as problematic, even though they had fewer drug patients than alcohol patients on their caseload. The GPs' reluctance to provide services to drug patients were attributed to either strong memories of "negative aspects of drug misusing patients' behaviour" or that the GPs had negative stereotypes of people who use drugs (Mistral and Velleman, 2001, p.69). My findings also suggested that OST patients were not supported by the clinical team within drug treatment services, in the alleviation of withdrawal symptoms during the titration phase. This means that OST patients are not offered support with withdrawal symptoms either externally or internally within drug treatment services during the titration phase.

Participants in my study stated that the prescription of Buvidal could help to address the barrier of withdrawal. Participants explained that the pharmacological properties of Buvidal could prevent the withdrawal between doses that is typical of other forms of substitute medication. Queensland Government (2019) explained in detail how the pharmacological action of Buvidal could prevent fluctuations of withdrawal and stability that is associated with other types of substitute medication. When Buvidal is injected, the interstitial aqueous fluid is absorbed by the fluid crystal formulation (Queensland Government, 2019). The fluid changes to a viscous liquid crystal which encloses the active substance (Queensland Government, 2019). This means

that there is a “slow and consistent release” of buprenorphine over the month, which could in turn prevent fluctuations between withdrawal and stability that is associated with other types of substitute medication (Queensland Government, 2019). Buvidal is clearly beneficial in the a) alleviation of withdrawal symptoms during titration and b) prevents fluctuations between withdrawal and stability that is associated with certain types of medication. However, the high cost of Buvidal at £239.70 for a 30-day supply may mean that this medication cannot be given to all OST patients (NICE, 2020). As explained earlier, the findings highlighted that there is inappropriate support within treatment services to address the barrier of withdrawal. Given the high cost of Buvidal, general health practitioners may need to be more involved in the support of OST patients, particularly for the treatment of cramps and disturbed sleep patterns during the titration phase. An OST patient in my study stated that treatment services should educate GPs on the importance of provision of support. Similarly, Mistral and Velleman (2001) recommended that GPs should be provided training but should also be given the opportunity to access expertise from drug treatment services. This support could enhance the efficacy of medical care provided by GPs to OST patients and help with achievement of progress in treatment.

### ***9.1.2 Effects of Buvidal medication***

Some participants stated that the ‘clarity of mind’ brought about by the cessation of heroin use that Buvidal treatment generated the ‘flooding’ of uncomfortable emotions, which triggered the use of heroin again. This ‘enforced abstinence’ was found to be particularly problematic for OST patients who were not ready to confront their emotions, particularly in the absence of appropriate counselling within drug treatment services. This finding corresponds with Notley et al.’s (2015) study which involved interviews with the long-term OST population (who had been in treatment for more than five years) and staff members at a rural drug treatment service. Notley et al. (2015) found that reduction of substitute medication resulted in the flooding of uncomfortable emotions associated with guilt of engagement in behaviours during periods of use and childhood. This in turn was found to strengthen dependence on substitute medication in the absence of appropriate coping strategies or psychological support (Notley et al. 2015).

While Notley et al.’s (2015) findings relate to the reduction of substitute medication, my finding relates to the clarity of mind associated with administration of Buvidal. However, the findings

are unified by the suggestion that both administration of Buvidal (*drug*) and reduction of substitute medication can result in the re-surfacing of uncomfortable emotions (*set*), which can be particularly problematic in the absence of counselling or appropriate support (*setting*). This suggests that treatment services should be particularly aware of circumstances that could give rise to the flooding of uncomfortable emotions and provide appropriate support. Notably, the *drug* barriers of reduction of substitute medication and administration of Buvidal were not wholly responsible for the discomfort of the flooding of emotions or dependence on substitute medication. The *setting* factor of absence of appropriate support contributed significantly to the negative impact of these distressing emotions. This was true in both mine and Notley et al.'s (2015) study.

The participants in Notley et al.'s (2015) study suggested that provision of support by ex-OST patients or volunteers and the provision of professional psychological support during reduction of medication, could help to address the barrier of the resurfacing of uncomfortable emotions. Similarly, the participants in my study stated that the provision of counselling at the site of the drug agency could help to address the flooding of emotions that is associated with the administration of Buvidal.

### ***9.1.3 Using heroin for self-medication***

Many participants in my study (including both staff and patients) stated that heroin is used to relieve emotional pain and symptoms of trauma. This use of heroin as a coping mechanism led to the development of the schema that heroin is an acceptable way of coping with emotions. Furthermore, participants explained that the occurrence of stressful situations (*setting*) increased the likelihood of their use of heroin as a coping mechanism to alleviate stress levels (*drug*). Similarly, Moran et al.'s (2018) study of long-term OST patients in Ireland, showed that heroin was consistently used as a coping mechanism in response to stressors in adulthood. It was understood that encounters with trauma and stress in adulthood were heightened among those with histories of childhood trauma who had difficulties in regulating their emotions (Moran et al. 2018). In such cases, substances such as heroin are valued, because it gives temporary relief from the pain of trauma (Moran et al. 2018). Furthermore, OST patients with previous traumatic experiences tended not to use positive relationships as a source of support, because relations with other individuals may have been negative in the past (Moran et al. 2018).

This could explain why some OST patients in my study continued to use heroin on a continual basis in response to stress, while engaged with OST. This could in turn prevent achievement of benefits from OST, because OST patients could be discharged from treatment services for use of heroin (as explained by participants in my study). This could mean that OST patients are not benefiting from treatment during the period of discharge. To address the problem of continual use of heroin in response to stress, both participants in my study and Moran et al. (2018) recommended that treatment services should support OST patients with management of stress to promote progression in treatment. Moran et al. (2018) emphasised that general practitioners, psychiatrists, counsellors and psychologists must also be involved in the effective management of stress of OST patients.

#### ***9.1.4 Using heroin for pleasure***

Many OST patients in my study stated that they continued to experience pleasure from heroin, while engaged with OST. Staff who described the difficulty of promoting progression in treatment and enhancing motivation levels among those OST patients still experiencing the pleasurable effects of heroin. Participants were divided in how treatment services should respond to the continual use of heroin while engaged with OST. One view was that OST patients should be detoxed because the purpose of substitute medication is redundant when heroin is used. However, the other perspective was that detoxification was counter-productive because it just strengthened the ‘revolving door’ of OST patients, where patients cycle in and out of treatment services without making any gains from OST. One potential solution to the problem offered by participants involved the provision of alternative pleasurable activities.

Valentine and Fraser (2008) conducted qualitative interviews with OST patients and treatment providers to explore the role of pleasure within OST, an issue which they noted “is often suppressed or submerged in policy or practice” (p.414). Similar to my study, the interviews highlighted the pleasurable effects of heroin and that the focus on reducing drug-related harm within services, meant that the role of pleasure in the use of heroin is neglected. In some respects, this could be termed the ‘elephant in the room’, where both OST patients and staff are aware of the pleasure of heroin, but the current design of treatment services does not allow for the concept of pleasure to be addressed within the delivery of interventions. In fact, an OST patient in Dennis’s (2021) study explained that ignoring the pleasurable effects of heroin,

sometimes meant that its use was not discussed within the therapeutic relationship. There is therefore a sense of “unspoken knowing” to avoid difficult conversations surrounding the need for drug tests and stricter dosing regimes (Dennis, 2021, p.1183). This ‘unspoken knowing’ creates in turn a sense of uncertainty within the practice of substitute medication prescribing.

In line with Dennis’ (2021) findings, a staff member in my study stated that some OST patients are forced into a situation where they have to be dishonest about their motives to enter treatment. In other words, OST patients state that they want to stop the use of drugs, when in reality they want substitute medication to help achieve stability within their lifestyle. Staff members also pretended to believe that the OST patient wanted to stop the use of drugs, when in reality they knew that the OST patient was not ready to do so. Over time this pretension caused a sense of exhaustion and contributed to the direct failure to achieve benefits from treatment. This is because the experience of repeated failures in treatment reinforced the message that OST patients are not capable of achievement of success in treatment.

Interestingly, none of the participants explicitly stated that pleasure should be acknowledged within treatment services. This tends to suggest that participants believe that the achievement of pleasure from heroin should be eliminated rather than embraced as an issue for discussion as part of the treatment process. This could be due to the traditional utilitarian view of treatment services that OST patients must avoid gaining pleasure from heroin (Valentine and Fraser, 2008). However, ignoring pleasure as a motivating factor is problematic in that it could prevent important therapeutic discussions about alternative pleasurable activities that are potentially less harmful and that could allow for better societal reintegration (e.g. sports, arts, crafts). It is interesting to note that while the Welsh Substance Misuse Delivery plan emphasises the need to reduce drug-related harms and address ACEs, it also recognises the value of providing alternative diversionary and sporting activities (Welsh Government, 2021). The continued use of heroin for pleasurable reasons when engaged with OST highlighted the need for commissioners to build diversionary activities into treatment budgets.

### **9.1.5 Low quality of heroin**

Participants in my study noted that the low quality of heroin meant that increased quantities of the drug were needed to alleviate withdrawal when doses of OST were too low to help (e.g. during the titration phase). Trafton, Minkel and Humphreys (2006) explained that heroin of low quality leaves the body more rapidly, which leads users to experience more frequent and more rapid withdrawal symptoms. This could explain why increased quantities of heroin are needed to alleviate withdrawal symptoms. The need for more heroin placed immense financial pressure on the OST patient (*setting*), which in turn increased the likelihood of offending behaviour or sex work. This finding aligns with those reported by May et al. (2019) who found that illegal drug users in Wales often used illicit substitute medication and/or other illicit drugs to enhance the effect of low quality heroin (*drug*). Given that polydrug use can increase the risk of toxicity and respiratory depression, it would be useful if services were able to monitor trends in purity (e.g. through self-report systems, ambulance data or drug testing schemes) in the local area so that appropriate warnings and harm reduction advice can be disseminated. Such measures may be more helpful than the use of penalties and punishments for polydrug use, which serve to intensify the marginalisation of people on OST and hinder progress in treatment (May et al. 2019).

An OST patient in my study also stated that staff members need to spend more time with the OST patients, so that they can know more about what is happening in the OST patient's life. The OST patient explained that spending more time with the OST patient could help with the identification of areas (such as low quality of heroin) that could have a detrimental impact on achievement of benefits from OST. This identification of problematic areas is important for the achievement of progress in treatment. In a similar vein, the OST patient recognised that limited financial and time resources within treatment services could mean that staff members have insufficient time to spend with OST patients. However, Dame Carol Black (2021) stated that every £1 spent on drug treatment services will result in £4 savings from reduced demands on health, prison, law enforcement and emergency services. This suggested that investment in drug treatment services and increasing the number of staff members (which could allow more time with the OST patient) within services is justified.

## **9.2 Set barriers**

The interviews with patients and staff also highlighted a number of barriers to progress that could be categorised as *set*-related using Zinberg's (1984) framework. These barriers were linked to the patients' low levels of confidence, patients perceptions of lack of visibility of successful treatment completions, their mistrust of treatment services, vulnerability, limited personal responsibility and lack of readiness to change.

### ***9.2.1 Low levels of confidence***

Many participants in my study expressed low levels of confidence in their ability to achieve success in treatment, particularly when they had long histories of drug use. This low level of confidence seemed to hold patients back and acted as a barrier to progress. Indeed, some OST patients felt that to succeed they would need long-term treatment that would enable them to address the complex issues associated with their long histories of drug use. The implication of this finding is that working with patients to improve their levels of confidence may help them to make progress and succeed.

However, increasing confidence alone may not be sufficient. Indeed, Moran et al. (2018) found that some OST patients' confidence in remaining opiate free was disproportionate to their actual achievements. The main driver for this overconfidence appeared to be a lack of understanding about the chronicity of opioid dependence and a lack of education about methadone treatment. Interestingly, none of the participants in my study described giving or receiving information about the chronicity of opioid dependency. In fact, most patients described being encouraged to reduce (rather than maintain) their substitute medication, although a small number of staff did believe that long-term prescription of substitute medication should be available to all OST patients. It may therefore be necessary to build confidence whilst also educating patients about dependence and about how OST works in practice.

### ***9.2.2 Mistrust of treatment services***

My findings suggest that mistrust of treatment services could affect the achievement of success from OST. Focus group discussions with service users of substance misuse agencies have

flagged up that issues around ‘trust’ and that sometimes trust issues are mistakenly interpreted as signs of resistance to engage with staff (Neale et al. 2015).

This mistrust manifests itself in different ways and at different levels, including: 1) patients’ mistrust in staff members or the ability of treatment to be successful, and 2) staff members’ mistrust in patients and in the ability of treatment to deliver successful outcomes. For instance, an OST patient in my study explained that he had disclosed his mental health issues to his keyworker in a treatment episode, who later failed to take any action on it. The passive attitude of the keyworker resulted in a feeling of mistrust and reluctance of the OST patient in sharing any more such information in subsequent treatment episodes. Therefore, the failure to address mental health issues directly contributed to mistrust in the efficacy of treatment services. This mistrust had a detrimental impact on engagement with therapeutic session. This is important because trust and engagement are needed for the delivery of successful therapeutic sessions. A staff member in my study explained that the keyworkers’ lack of action could be because the skillset of staff members (*setting*) within drug treatment services, is inadequate to meet the complex psychological needs (*set*) of OST patients.

Moran et al. (2018) make a similar point and highlighted that staff members are not adequately trained to address mental health issues with which their clients present. One participant in their study stated that the psychiatric team only addressed dependence at the expense of neglecting the treatment of mental health issues. Dame Carol Black (2021) notes that there has been a significant decline of substance misuse psychiatrists within drug treatment services and specialised substance misuse social work teams and that drug workers are not adequately trained to deal with clients with complex mental health issues. Moran et al. (2018) recommended that mental health workers should be trained in substance misuse issues and substance misuse workers should be trained in mental health issues. The chaotic lifestyle of some OST patients could further exacerbate the problems associated with diagnosis of mental health needs, as OST patients may miss medical appointments (Moran et al. 2018).

One OST patient in my study stated that staff members had responded to a positive drug test in an unhelpful manner by assuming that she had used heroin when in fact she had used painkillers

prescribed to her by her dentist to treat toothache. This incident resulted in the OST patient losing her trust in staff members (*set*) which in turn had a negative impact on her therapeutic relationship with her keyworker. Likewise, some staff members in Strike and Rufo's (2010) study stated that the process of urine testing was detrimental to the development of trust within the therapeutic relationship because returning a positive test could result in patients losing their OST prescription. This possibility, which was highlighted by some of my participants too, generated increased anxiety among OST patients. Faced with the daunting prospect of losing their medication, patients preferred to use dishonest tactics such as tampering with urine samples and not admitting having used heroin to their keyworker. This is important because honesty is one of the most important features of a successful therapeutic relationship.

One issue that my participants indicated as a cause for OST patients' mistrust in the ability of OST treatment to be successful was the inconsistent delivery of evidence-based interventions. For instance, some staff members noted that the delivery of unsuccessful informal interventions in previous treatment episodes resulted in patients' mistrust of the need for and usefulness of more intensive interventions in future treatment episodes. This mistrust wasted valuable time because it meant patients who had previous negative experiences with simpler interventions were reluctant to engage properly in more complex psychosocial sessions. In Dennis's (2021) study, OST patients also highlighted inconsistent ways in which staff members delivered OST treatment. In this case, some staff members were more lenient to the use of heroin than others, which resulted in a feeling of uncertainty of prescription regimes among OST patients. This uncertainty manifested in different ways in my and Dennis's (2021) studies. In my study the variation emerged from differences in the delivery of psychosocial interventions, while in Dennis's (2021) study the inconsistency resulted from differing responses to the use of heroin. Both these inconsistencies had differing implications on the wellbeing of OST patients. First, it generated mistrust in the ability of OST to be successful among patients, and second it led to wastage of time resources and created uncertainty in prescription regimes.

An OST patient in my study who had previous experience of working in a drug agency stated that it was easy to lose hope with long-term OST patients who had struggled with treatment. This 'losing hope' directly affected achievement of benefits from OST because it resulted in some cases in the delivery of the bare minimum of interventions: McCartney (2022) also

referred to the concept of therapeutic nihilism, where staff hold the view that some OST patients will never achieve recovery. This concept of therapeutic nihilism can be explained by clinical fallacy i.e., staff members are exposed to relapses and challenging behaviour on a continual basis because people who succeed often leave treatment services (McCartney, 2022). This clinical fallacy results in underestimation of progress of OST patients, which in turn is associated with increased risk of relapse McCartney (2022). So, how can this therapeutic nihilism be addressed to promote progression in treatment? McCartney (2022) stated that hope of staff members is vital to increase motivational levels of OST patients, and for them to succeed in treatment. The employment of staff with lived experience is a powerful way of introducing ‘hope’ in both OST patients and staff members within drug treatment services (McCartney, 2022). This solution resonated with me on a personal level, because when I was working as ‘active treatment worker’, I gained both invaluable advice and support from staff members with lived experience. The absence of visibility of success within treatment services clearly contributed to a lack of belief amongst staff members that OST patients will achieve success in treatment. Similarly, the invisibility of successes in treatment services contributed to mistrust in the efficacy of treatment services amongst OST patients too.

### ***9.2.3 Mistrust of efficacy of treatment services and lack of visibility of successful treatment completions***

OST patients in my study said that the lack of visibility of successful treatment completions contributed to mistrust of the efficacy of treatment services. Rosenbaum and Murphy’s (1984) study of female OST patients highlighted that their participants had limited or no knowledge of OST patients who were successful in their treatment. Interestingly, more than thirty years on, an OST patient in my study also explained that given he did not know of people who completed OST successfully he did not have confidence that treatment services would help him achieve success in treatment either. This lack of visibility of successful treatment stories might be because OST patients who have achieved abstinence from both heroin and substitute medication tend to distance themselves from drug treatment services to avoid contact with the drug-using network and the clinical environment of drug treatment services (Rosenbaum and Murphy, 1984). Schwartz (2014) explained that this ‘invisibility of success[ful]’ examples within treatment services means that staff members are only in contact with OST patients who have relapsed, have entrenched problems or have failed in OST. This strengthens the belief of staff members that OST patients will not recover from their dependency (Schwartz, 2014).

An OST patient in my study stated that by employing staff members with lived experience, drug services could increase the visibility of individuals who have succeeded in treatment and therefore provide positive examples for their cohort of OST patients. A similar point was made by Dame Carol Black (2021) and The CFE Research and the University of Sheffield (2021, p. 9), who highlighted the importance of employing people with lived experience within drug treatment services because these can constitute “powerful role models to others experiencing substance misuse, homelessness and poor mental health, demonstrating that recovery is possible”.

Many participants in my study referred to the presence of staff members with ‘lived experience’ at the drug agency. Likewise, CFRUS (2021) reported that the Birmingham Changing Futures Lead Worker Peer Mentor programme is one example where individuals with lived experience of drug use are given the opportunity to work in peer mentor roles. Some participants in this study expressed concerns that the relapse of staff members with lived experience could increase the likelihood of relapse in other OST patients, but the risk of this happening was lower than anticipated and could be further mitigated through the provision of appropriate support for those at risk. Similarly, Best (2019) argues that the employment of individuals with ‘lived experience’ is one way of increasing the visibility of treatment success, because they provide a model of inspiration and convey the belief that recovery is possible.

Best (2019) further states that another way to show patients in treatment that recovery is possible, is to engage them with a diverse range of individuals (not necessarily with lived experience). The author provides the example of the Sheffield Addiction Research Group who organise a variety of events such as a music festival, a bike ride and a Christmas meal that are attended not just by drug treatment patients, but also academics, professionals and members of the community. A staff member in my study agreed with Best’s (2019) argument and stated that drug treatment services need to provide opportunities for OST patients to develop links with people who have no connection to drugs because this can enhance their recovery prospects. The staff member also emphasised that OST patients should be offered opportunities to access taster courses and work placements and suggested that the development of links with

non-drug treatment related individuals could help to address stigma against people who use drugs and promote integration.

To sum up, the lack of visibility of treatment successes within treatment services (*setting*) contributes to a lack of confidence in their efficacy (*set*). Employment of people with lived experience (*setting*) could help in addressing this issue because individuals who proved to be successful in treatment could become inspirational role models and provide evidence that recovery is possible. A further way to increase OST patients' confidence in a successful treatment outcome would be to include the community with no lived experience in the recovery process because it is thought this would increase patients' recovery capital, access to employment opportunities and to address stigma.

#### **9.2.4 Adverse childhood experiences (ACEs)**

The Welsh Government (2021) describe ACEs as the occurrence of traumatic incidents in childhood which can result in poor outcomes across the lifespan of the individual. Those with a history of a four or more ACEs are sixteen times more likely to use heroin, crack or cocaine (Welsh Government, 2021). By the age of 49, 24.9% of individuals with four or more ACEs are diagnosed with chronic diseases. Comparatively, only 6.9% of individuals with no ACEs are diagnosed with chronic diseases by the age of 49. These statistics suggest that a significant proportion of OST patients will have ACEs. In Moran et al.'s study (2018), the existence of ACEs among their participants resulted in an inability to cope with stress (*set*), which in turn resulted in the continual use of heroin in response to stress (*drug*) in adulthood. Conversely, in my study ACEs had an adverse impact on the ability of OST patients to trust others. This in turn had an adverse impact on trust (*set*) within the therapeutic relationship and affected achievement of benefits from OST. The association between ACEs and continual use of heroin/low levels of trust within the therapeutic relationship highlighted the need for services to provide more specialised counselling and trauma support, which links into the previous section about keyworkers not being sufficiently trained to deal with mental health issues. Additionally, OST patients stated that the busyness of treatment services meant that there was insufficient time to address ACEs or mental health issues. An OST patient explained in my study that he left the treatment service because he perceived that staff had no time to listen to his issues. This could mean that important issues of the OST patient remain unaddressed which could impede

progression in treatment. The decline in the number of staff members working in the field of substance misuse and high caseload of staff members (40-100) could contribute to the busyness of treatment services and have a detrimental impact on the quality of care that is offered to OST patients (Dame Carol Black, 2021). To resolve this barrier, Dame Carol Black (2021) recommended the development of a strategy that aims to increase the incidence of professionally qualified drug treatment staff within treatment services such as doctors, psychologists, therapists, nurses and social workers.

### ***9.2.5 Lack of readiness to change***

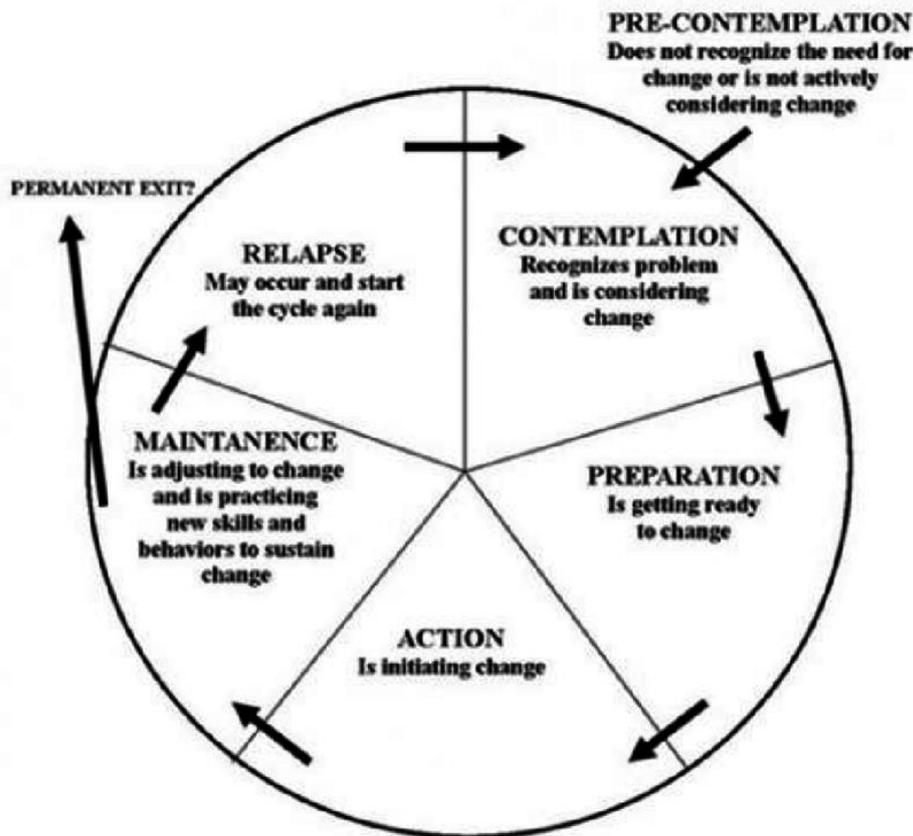
Some OST patients in my study felt that the achievement of success from treatment was dependent on their 'readiness' to change (*set*). Furthermore, there was agreement among staff and patients that OST patients cannot be helped if they are not ready to stop their use of heroin. However, this did not mean that all OST patients were ready to change, or willing to stop their use of illicit drugs. In fact, as one OST patient explained, there are many OST patients there who are not ready to stop their use of heroin, but who may still access the treatment service for a variety of other reasons such as to get support with housing, or because of requirements imposed on them by the criminal justice system.

Moreover, my study revealed that changes in drug treatment which are forced upon patients without their will might have a detrimental impact on treatment success. For instance, one OST patient stated that if drug workers pressured him to stop using heroin when he was not ready to make this step, his response would be to increase his consumption of heroin as a form of retaliation. Similarly, some participants in Notley et al.'s (2015) study stated that the pressure to reduce substitute medication by treatment services when OST patients are not ready could be counterproductive because it could lead to relapses and a general failure to benefit from treatment.

According to Prochaska and DiClemente's 'Cycle of Change' (presented in Fig. 1 below) engagement with OST services might be suggestive of the patient being in the 'action stage', (i.e. that the patient has initiated a change towards recovery). However, what my findings suggest is that some OST patients may in fact be in the 'pre-contemplation' stage with regard

to their willingness to change. In other words, simply being in treatment may not be indicative of readiness to change. All these findings point to the proposition that treatment services may need to carefully match interventions to the state of 'readiness' of the OST patients.

Fig.1 Prochaska and DiClemente Cycle of Change (Murphy, 2011, p.8).



Some participants stated that increasing OST patients’ recovery capital during the stages of unreadiness (i.e. housing, debt) and the introduction of two strands of treatment based on readiness to change (one focused on abstinence and one on harm reduction) could help to address the barrier of ‘unreadiness’. Similarly, Notley et al’s (2013) systematic review of studies that explored barriers within the long-term OST population found that some studies advocated for two strands of treatment (harm reduction and abstinence) based on readiness to change. Intrinsic motivation is often triggered by non-treatment related factors (Moran et al. 2018), but my findings suggest that the delivery of appropriate interventions (*setting*) during states of unreadiness could still help with achievement of benefits from OST. Neale et al. (2011) also acknowledges that harm reduction and abstinence approaches are not separate entities but should be viewed as a continuum, as the achievement of abstinence is not incompatible with the principles of harm reduction. Participants in my study explained how OST patients should be given the opportunity to alternate between the strands of treatments

based on their readiness to stop their use of heroin. The matching of OST patients to different strands of treatment based on ‘readiness’ highlighted the importance of the adoption of an individualised approach that meets the specific needs of the OST patient.

### **9.3 Setting barriers**

The existence of long waiting lists for substitute medication, an overemphasis on achievement of abstinence, a focus on the importance of medication, impact of treatment on lifestyle, lack of recovery capital, stigma and the absence of planned treatment exits were all perceived to be *setting*-related barriers for treatment success. Each of these will be addressed in turn below.

#### ***9.3.1 Waiting list for substitute medication***

The World Health Organization (WHO, 2009a) and Welsh Government (2011) stipulate that OST must be accessible to all individuals that need it, including people in prison. However, the Healthcare Inspectorate Wales’s (HIW) (2018) review of substance misuse services in Wales found that there was a significant waiting period for substitute medication in Wales. The same problem was reported by patients and staff in my study too. This means that the Welsh Government’s (2011) commitment regarding the accessibility of substitute medication is not being followed.

One serious implication of this gap in provision is that OST patients are not getting the treatment that they need and are therefore not able to achieve positive treatment outcomes. OST patients in my study stated this waiting period resulted in financial difficulties, entrenchment of drug use and perpetration of offences. Participants in both my study and the HIW (2018) review stated that the failure to rapid access to medication, means that the opportunity to engage OST patients at the optimal period of motivation is lost. This could mean there is a cohort of OST patients who are not ready to stop their use of heroin within drug treatment services. This is because by the time that they access substitute medication, the optimum levels of motivation are lost. The HIW (2018) recommended that area planning boards should consider how waiting times could be reduced. My study has also highlighted the importance of providing rapid access to substitute medication at the point of need. However, there were notable concerns among some participants surrounding the need for preparatory psychosocial sessions, prior to the

prescription of substitute medication. However, HIW's (2018) suggestion that motivation is optimal at the point of approaching treatment, questions the need for preparation. Indeed, time spent preparing delays entry into treatment, which may have an adverse impact on levels of motivation. Rapid access to OST is especially important given my findings of reduced efficacy of psychosocial sessions during the waiting period.

### ***9.3.2 Over emphasis on achievement of abstinence***

KPI five emphasises that treatment services must have an “increased number of ‘treatment completed’ closures” (Welsh Government, 2021, p.11). According to the KPI, “treatment completed will be deemed as either problematic substance free or by client reaching treatment goal(s) as agreed at the commencement of treatment” (Welsh Government 2021, p.10). KPI five raises two important issues: 1) that abstinence from heroin and achievement of mutually agreed goals will be deemed as success in treatment, and 2) the focus on completion and exits suggests that there is pressure on treatment services to reduce the substitute medication of OST patients rather than support maintenance on substitute medication on a long-term basis.

Prior to the discussion of abstinence from heroin, it is important to reflect on what ‘abstinence’ actually means to OST patients. Neale et al.'s (2011) interviews with recovering heroin users highlighted that ‘abstinence’ means different things to different people. For example, abstinence for some patients was defined as stopping the use of their problematic substance but continuing with controlled use of other substances. Similarly, in my study an OST patient felt strongly that treatment services should not challenge his polydrug use because he was only in treatment for the use of heroin. This is evidence that OST patients reviewed the definition of abstinence in different ways.

Participants in Neale et al.'s (2011) study expressed a desire for abstinence but were unsure of their capability to achieve this goal for a variety of reasons such as cravings, the beneficial effects of heroin as a coping mechanism for stress, contact with the drug-using network, limited willpower or histories of failed attempts to achieve abstinence from heroin. Similarly, participants in my study were also doubtful of their ability to achieve abstinence from heroin and while they offered comparable explanations they also described other reasons too

including: unaddressed mental health issues, ACEs and in some circumstances not understanding the reasons for their use of heroin. It is unclear if this perceived inability to achieve abstinence stems from therapeutic nihilism (as discussed earlier in the chapter) or ACEs/mental health issues. The discussion on therapeutic nihilism suggested that provision of support for ACEs/mental health and having belief in the OST patient's ability to change could promote progress in treatment.

One staff member in my study explained that the achievement of abstinence might be an inappropriate goal for OST patients who have suffered childhood trauma. A similar point was noted by McKeganey et al. (2004) who concluded that the achievement of abstinence might not be a realistic goal for all OST patients, even if they wanted it. Indeed, it was felt that setting such ambitious goals could "be more damaging and demoralizing for drug-agency clients" (McKeganey et al. 2004, p. 433). Instead, the authors suggested it could be more productive to focus on significant harm reduction measures which are more realistic and which, if successful, could increase clients' self-esteem and belief in their ability to change. A staff member in my study agreed and stated that the setting of 'abstinence' goals for some OST patients can be counterproductive. This is because it was seen to have resulted in repeated failures to achieve abstinence, which became a barrier to success because it reinforced the message that the OST patient could not be helped.

KPI five does not explicitly state that all OST patients must exit treatment. However, as explained before, it does allude that exits from treatments will be deemed as success. Participants within the study recognised that there was a growing expectation within generic drug treatment services, and not just the CJS, of the need for reduction rather than maintenance on OST. Some OST patients who perceived that they needed long-term maintenance of substitute medication were encouraged to access shared care programmes under the supervision of their GP. It is unclear if this stems from the desire to increase availability of specialist treatment spaces, especially given the waiting list for substitute medication (as expressed by some participants), or from the pressure to meet KPI 5, or a combination of both these factors.

It is noteworthy that Rosenbaum and Murphy (1984) cautioned that rapid, severe and involuntary detoxifications (*setting*) could result in expectations of undesirable effects of reduction of substitute medication or fear (*set*), which could in turn prevent attempts at reduction of substitute medication. This suggests that treatment services must carefully: assess

whether the OST patient is capable of reduction of substitute medication, assess if he/she is ready to reduce substitute medication, and offer appropriate support during the process of reduction (as stated by participants in the study). In other words, treatment services must use a individualised approach that is based on the capability of the OST patient to reduce OST medication and readiness of the OST patient at the given time. This could in turn decrease the incidence of failed detoxification attempts.

To summarise, patients and staff report varying definitions of abstinence and some patients (and some staff) do not believe that abstinence is always an achievable goal. The standardised definition of abstinence (*setting*) by treatment services appears to be incompatible with the individualised descriptions of treatment success and the finding that some OST patients are incapable of achieving abstinence.

### ***9.3.3 Focus on the importance of medication***

Participants in my study stated that the ‘focus on the importance of medication’ by treatment services meant that the role of personal responsibility for engaging and participating in treatment was often ignored. The focus on medication also lowered self-efficacy levels, because OST participants attributed success in treatment to the medication rather than themselves. As explained earlier, the ‘focus on the importance of medication’ sometimes also resulted in anxiety of losing substitute medication. Similarly, participants in Notley et al.’s (2015) study stated that the overemphasis on prescription of substitute medication resulted in a failure of treatment services to address the underlying reasons for the use of drugs.

OST patients in my study further elaborated and stated that the over-emphasis on the prescription of substitute medication has meant that more appropriate holistic treatment is not delivered to meet patients’ complex needs, such as building structure in the day, addressing mental health issues and development of appropriate coping mechanisms to handle stress. One patient explained that the failure to meet these needs had resulted in his continual use of heroin to cope with boredom, mental health difficulties and stress. This suggests that treatment services must be vigilant of how the broad range of needs of OST patients can be met by treatment services and also how they can refocus their attention to areas that are deemed to be of importance to the OST patient. Furthermore, this failure to meet the broader needs of the

OST patient conflicts with Department of Health (2017) guidelines that treatment services must address the health and social needs of OST patients too.

#### ***9.3.4 Negative impact of treatment rules/regulations on OST patients***

Many OST patients expressed compliments about the treatment that they had received within the treatment service. However, participants also described how the need to pick up substitute medication daily interfered with participation in other activities. For instance, treatment was perceived to interfere with family life and planning of holidays, which might both be considered to be indicators of success in treatment. The interference of treatment with holidays was perceived to be magnified for OST patients with families living abroad. The long duration of trips to visiting family members on some occasions meant that patients were discharged for non-attendance of appointments. More worryingly, the difficulties in getting large supplies to take away meant that some OST patients were coerced into a situation where they had to use heroin because they had insufficient supplies of substitute medication.

Buvidal is a prolonged release solution of buprenorphine in a pre-filled syringe (Datapharm, 2020). Participants in my study stated that administration of Buvidal could minimise the interference of treatment with lifestyle, because it allowed the OST patient to go on holiday without the need of transportation of huge quantities of substitute medication. The injection of Buvidal also eliminated the risks of misuse and diversion. However, despite these important benefits of Buvidal, there were mixed perspectives on the suitability of Buvidal for chaotic OST patients. One particular concern was that Buvidal removes regular contact with the drug agency, which could mean that non-drug related risks are not monitored. This concern mirrored Addiction Professional's (2020) caution that the administration of Buvidal was related with loss of contact with the drug agency. A possible solution could be to refer individuals to non-drug services which can cater for their needs. An added benefit is that the barrier of stigma attached to attending a drug service and the danger of mingling with the same drug using peers would also be addressed. Accessing support services outside of the drug agency could also provide opportunities for reintegration.

However, more positively, it was also recognised in my study that administration of Buvidal ensured compliance with medication, particularly for OST patients at risk of domestic violence.

This was also reported in Hard's (2021) Welsh case studies of individuals who were administered Buprenorphine. In one particular case study, the individual was unable to attend appointments because of his chaotic lifestyle. Administration of Buprenorphine was subsequently related with compliance with medication, negative drug test results, stable housing, improved relationships, cessation of offending behaviour and engagement in hobbies (Hard, 2021). These conflicting perspectives surrounding the prescription of Buprenorphine for chaotic OST patients suggest that treatment services must carefully balance the risk of loss of contact with adherence with medication (Addiction Professionals, 2020). The uncertainty surrounding the prescription of Buprenorphine for OST patients highlights the importance of the adoption of an **individualised** approach that considers the specific risks of each OST patient on a case-by-case basis.

### ***9.3.5 Lack of recovery capital***

Many participants stated that they tried to avoid their former drug-using networks to avoid the temptation of using heroin. However, their regular encounters with these networks at the pharmacy and drug treatment services meant that they were regularly faced with the temptation to use heroin, pressure to sell medication or coercion to purchase heroin. This in turn affected the achievement of success from OST. Similarly, methadone maintenance patients in Anstice et al.'s (2003) study stated that they tried to distance themselves from the drug using network, to avoid triggers associated with the use of heroin. However, encounters with former peers or individuals during the dispensation of substitute medication who were selling/using drugs resulted in the temptation to use heroin. Anstice et al. (2003) stated that limited choices in the sites of dispensing (*setting*) could exacerbate the influence of the barrier of the drug-using network. However, pragmatic factors such as availability of staff and a lack of dispensing spaces may mean that treatment services are not able to offer any alternatives. An OST patient in my study suggested that seeing OST patients for appointments on an 'one in, one out basis' (which worked well during the COVID-19 lockdown period) could prevent congregation in the waiting room and prevent encounters with the drug-using network.

While severing contact with drug-using networks was described as an important goal, this was not sufficient in itself to ensure treatment success. Indeed, participants in my study reported experiencing difficulties in forming new friendships that would help support a drug-free lifestyle. One patient, for example, described difficulties in forming friendships with people

who do not use drugs because of concerns that any disclosures about drug use would be met with stigmatising comments. Notley et al.'s (2013) review of qualitative research also found that the desire to maintain secrecy about the stigmatising act of heroin use was a barrier to the development of new friendships. Notley et al. (2013) recommended that OST patients should be offered psychological support or counselling that focusses on improvement of self-esteem levels, particularly in relationship to the development of new friendships.

Many OST patients in my study described how social isolation (from former and new networks) stated that they experienced boredom, loneliness and a general void following their abstinence from heroin. A staff member was concerned that for some patients this increased the likelihood of use of heroin. Similarly, in Moran et al.'s (2018) study, the living and social environment of many OST patients provided limited opportunities for developing a sense of purpose (Moran et al. 2018). This lack of purpose contributed to boredom and loneliness, which in turn resulted in continual use of heroin (Moran et al. 2018). This resonates with Best's (2019) proposition that jobs, friends and houses are needed for the achievement of recovery. This strongly suggests that mere abstinence from heroin is insufficient for the achievement of success in treatment. In fact, OST patients in my study emphasised that abstinence did not automatically result in improved quality of life, especially in the presence of financial pressures or absence of purpose. OST patients stated that improved relationships with family members contributed to the improved quality of life following the achievement of abstinence from heroin. Similarly Best et al's (2008) study of desistance factors showed that distance from drug using network and support from non-drug using network were key factors that contributed to maintenance of abstinence from heroin. My findings and research (Best, 2019; Best et al. 2008) suggested that treatment services need to focus on enhancement of recovery capital (e.g. jobs, friends and houses) and not just address the use of heroin.

### ***9.3.6 Stigma***

Conner and Rosen's (2008) qualitative study of methadone maintenance patients aged 50 or over showed that this population experience multiple stigmas associated with drug dependency, aging, using psychotropic medication, depression, engagement with methadone maintenance, poverty, race and HIV status. The three most prevalent stigmas were aging, the use of psychotropic medication and depression. Many OST patients in my study also reported that

they experienced stigma in a number of ways. This was manifested in aspects such as exclusion from mainstream societal activities, such as going to the pub and the formation of new friendships. More importantly, the stigmatised views held by some professionals meant that OST patients did not always receive the support that they needed. In Connor and Rosen's (2008) study, participants stated that they did not disclose their methadone treatment status to doctors because of the fear of being stigmatised and not believed. These fears proved to be true as the discovery of engagement with OST resulted in deterioration of the relationship between the doctor and the OST patient, because the doctor doubted his need for opioid based painkillers (Moran et al. 2018).

This lack of honesty with healthcare professionals is of particular concern because doctors could erroneously prescribe medication that is incompatible with methadone (Connor and Rosen, 2008). Similarly, in my study an OST patient explained that her previous stigmatising experience with doctors meant she no longer visited her doctor for treatment of health issues. This resulted in the use of heroin to 'medicate' the health issues. This neglect of treatment of health issues, could in turn have an adverse impact on the general wellbeing of the OST patient and hence on treatment outcomes. What is noteworthy is that the continual use of heroin could have been avoided if the patient's health issues had been addressed in an appropriate and non-stigmatising manner by the doctor. The greater involvement of GPs and other healthcare professionals in the treatment of people with substance misuse problems could go some way towards reducing these stigmatised views.

The above discussion strongly suggests that stigma can have an adverse impact on the achievement of benefits from OST. A participant in Moran et al.'s (2018) study recommended that the public should be educated about the purposes of treatment services and encouraged to avoid terminology that has negative connotations. One way of educating the members of the public could be through the provision of opportunities that promote integration, as suggested by one of the participants in my study. The participant stated that the provision of opportunities of reintegration such as access to taster courses and work placements, could allow the public to get to know OST patients as individuals and address the stigma of people who use drugs.

Best (2019, p.14) also emphasised the importance of the social recovery capital, which can be described as “the social supports the individual can draw upon to support their recovery journey.” This accumulation of social recovery capital enhances accessibility to resources in the community and also creates responsibilities through social interactions (Best, 2019). This enhanced accessibility to social resources has the potential to reduce deaths from drug overdoses (Best, 2019). The creation of obligations through the accumulation of social recovery capital could enhance personal responsibility, which was deemed to be an important factor in the achievement of success from OST in my study. The conflicting perspectives surrounding the importance of staff members with ‘lived experience’ in my study, supports Best’s (2019) postulation that it is the **strength** of the relationship with these positive social networks that determines the accumulation of social recovery capital.

Participants in both my and Moran et al.’s (2018) study recommended the adoption of a multi-sectorial approach that involved the co-location of psychiatric and housing services within drug treatment services, to improve accessibility to other forms of support. As Best (2019) stated, reintegration with society could enhance accessibility to resources which could in turn promote achievement of success in OST. However, participants in my study expressed concerns that the co-location of external services could strengthen institutionalisation and threaten the need for integration with mainstream society. One solution could be for treatment services to build partnerships or “bridges” with external support services and resources in the community (Best, 2019, p.12). Radcliffe and Stevens (2008, p.1072) also stated that treatment services must enable OST patients “to build the sort of social capital that supports recovery (e.g., contacts that link them to the world of work and legal leisure activities) rather than being enclosed within a world where their only contacts are with drug workers, users and dealers.” A staff member in my study agreed and stated that the failure of treatment services to provide opportunities for reintegration and subsequent accumulation of social capital has resulted in the congregation of people who use drugs outside of drug treatment services. This has resulted in the strengthening of stigma against people who use drugs, which in turn could have a negative impact on achievement of benefits from OST. This could increase motivational levels for achievement of recovery, increase accessibility to resources in the community and enhance recovery capital such as self-esteem self-efficacy, communication skills, coping skills and resilience” (Best, 2019, p.14). This emphasised that the community must also be involved in the achievement of success from OST.

### ***9.3.7 Absence of planned exits in treatment***

Staff members in my study highlighted that there were no planned exits for OST patients within drug treatment services. This absence of planned exits within treatment services has resulted in wastage of valuable time resources and retention of OST patients in treatment services who may no longer need treatment. This is of particular concern, especially given the earlier discussion about the long waiting period for substitute medication. Furthermore, participants in my study stated that the absence of planned treatment exits and the prolific occurrence of unplanned exits could mean that OST patients are cycling in and out of treatment services, without making any gains from treatment. Worryingly, the risk of overdose is highest at the termination of treatment episodes (*setting*) because of reduced tolerance levels of heroin use (*drug*). Prenoxad Injection (2019) state that this increased risk of overdose highlights the urgent need to increase the number of planned exits, where support and guidance (and naloxone kits) are provided to patients leaving treatment. Participants in my study suggested that the incidence of planned exits should be encouraged and could be increased by the use of regular reviews and the setting of clear long-term goals at the commencement of treatment.

### **Conclusion**

To the best of my knowledge, this study is the first to use Zinberg's (1984) *drug, set and setting* theoretical framework to identify treatment related barriers faced by the long-term OST population in achieving benefits from OST. The use of this theoretical framework was beneficial because it helped to improve understanding of how the barriers interact in different ways to affect the wellbeing of the OST patient. Another unique aspect of my research was that it included OST patients who have been engaged with OST for more than five years on a continuous or intermittent basis. This is of particular importance given the increased risk of overdose at the termination of treatment episodes (Prenoxad Injection, 2019).

Furthermore, most research on the barriers faced by the long-term OST population has focussed largely on OST patients who are prescribed methadone. This could be because buprenorphine patients who are not ready to stop their use of heroin, are more likely to leave treatment because of the blocking effects of medication and are therefore not eligible for inclusion in research studies (Evans et al. 2019). However, the inclusion of long-term OST patients with intermittent

engagements has allowed me to capture the perspectives of OST patients who have experience with buprenorphine as well.

The introduction of the administration of the prolonged release buprenorphine during the time of the COVID-19 pandemic and my fieldwork, has also allowed me to gain the unique perspectives of long-term OST patients and staff members on the use of Buvidal as both a barrier and facilitator of success in OST. In addition, there has been limited research in Wales on the barriers faced by the long-term OST population and also how these barriers can be addressed. This is particularly important given the different drug policies within the UK, which means that the experience of barriers could be different for the Welsh OST population.

This chapter identified that the lack of appropriate support to meet the complex needs of OST patients has a detrimental impact on achievement of benefits from OST. One novel finding was that the discussion in Buvidal, identified the absence of appropriate support to address ACEs/mental health issues. The findings suggested that treatment services are failing to provide support with withdrawal during the titration phase, management of stress and ACEs/mental health issues. This failure to provide adequate support has resulted in the continual use of heroin while engaged with OST, increased vulnerability of the influence of the drug using network, mistrust in the efficacy of treatment services and subsequent non-engagement in therapeutic sessions, which in turn can affect achievement of benefits from OST. These factors could in turn contribute to limited visibility of treatment successes within drug treatment services, which in turn was associated with therapeutic nihilism in staff members and mistrust of efficacy of treatment services in OST patients. Both these factors could affect achievement of benefits in OST.

This failure to provide adequate support to meet the complex needs of OST patients can be related to inadequate training of staff members within drug treatment services. Training staff members within drug treatment services could mean that mental health issues of OST patients are met. However, given the busyness of the treatment services (as identified in this thesis), it is unclear if staff members within drug treatment services will have any time to address mental health issues in depth, other than identification of mental health issues and signposting to relevant services. This chapter identified that the needs of OST patients are not met externally

either for a variety of reasons such as stigma of some health, long waiting lists etc. One solution could be the co-location of support services within treatment services, but this could mean that OST patients continue to be dependent on treatment services for a longer period of time. To address this issue, GPs could be supported in accessing the expertise of substance misuse services and partnerships could be developed with external support services. This partnership could build ‘bridges’ with the community and empower OST patients to access resources within the community (Best, 2019). Additionally, this development of social capital could also help to address the barrier of stigma and promote progression in treatment. The involvement of GPs, external support services and the community in the care of the OST patients could also help to reduce burden on treatment services that are already overstretched.

For instance, this chapter also identified that staff members within treatment services do not have sufficient time to address the needs of the OST patients in depth. For instance, the busyness of the treatment services resulted in OST patients not disclosing their issues to staff and unawareness of staff members of potential issues that could impede progression in treatment. Dame Carol Black’s (2021) suggested the employment of more members of specialist staff within drug treatment services, which could in turn increase the availability of time resources.

The absence of opportunities for integration within treatment services has strengthened stigma (against people who use drugs) and dependency of OST patients on treatment services. Similar, to the discussion on lack of appropriate support, treatment services should build ‘bridges’ with community services to enhance social capital.

This chapter has highlighted that treatment services have failed to provide an individualised approach that meets the specific needs of OST patients. For instance, the needs of OST patients were found to differ based on readiness and capability to achieve abstinence/reduction of medication. The use of a standardised approach by treatment services has resulted in the delivery of inappropriate interventions that does not match the ‘readiness’ of the OST patient. One solution that has emerged from the study is that OST patients should be given the opportunity to move between strands (abstinence and harm reduction) of treatment, based on their ‘readiness’ (*setting*), to stop their use of heroin. The utilisation of a standardised approach

has resulted in repeated treatment failures, which in turn strengthened the belief of the OST patient that he/she is incapable of achievement of treatment success. This suggested that treatment services need to adopt an individualised approach that meets the specific needs of the OST patients and considers important factors such as history of ACEs. This solution is positive because it considers the fluctuation of motivational levels.

The negative impact of treatment rules/regulations on OST patient's lives was also deemed to be an important barrier that could affect the wellbeing of the OST patient. For instance, the treatment rules interfered with family life, planning of holidays and employment. The monthly administration of Buvidal could offer greater flexibility and address some of these concerns. However, there were concerns that the monthly administration of Buvidal could mean that non-drug related risks are not monitored.

One important finding that emerged from this chapter was the need others (community, health professionals, psychiatrists etc) to be involved in the treatment of the OST patients, which could mean that more benefits are achieved from OST. This chapter has aimed to discuss the findings in the context of existing literature. The next chapter will discuss in more detail the implications of these findings for policy, practice and future research. The next chapter will also consider adaptations to Zinberg's (1984) *drug, set and setting* framework in the light of findings from this thesis.

## CHAPTER TEN - Conclusions

### Introduction

This final chapter reflects on the previous results and discussion chapters, and considers the implications for policy, practice, future research and wider application of Zinberg's (1984) *drug, set and setting* framework. Previous research has clearly established that OST is beneficial in improving the health and wellbeing of people who are dependent on heroin. However, there is a small cohort of patients who are not making any treatment gains from OST, despite long-term engagement with treatment services. The research on which this thesis is based aimed to improve understanding of the barriers faced by this cohort of long-term OST patients in achieving success from OST. The research also sought to identify solutions that could address these barriers, promote progression in treatment, and subsequently improve the health and wellbeing of OST patients who are not gaining benefits from OST.

To achieve the above-mentioned aims, the following qualitative research methods were used:

- 1) Interviews with the long-term OST population who have been engaged with OST for five years or more on a continuous or intermittent basis.
- 2) Interviews with staff members who have direct experience of working with the long-term OST population.
- 3) A 'microethnography', which involved regular visits to the various sites of the drug agency across South Wales where OST and psychosocial support are provided.

To the best of my knowledge, this is one of the first studies that has used Zinberg's (1984) *drug, set and setting* framework to a) identify barriers to achievement of success for long-term OST patients, and b) identify solutions that could improve the health and wellbeing of OST patients who are not making gains from long term OST. Most research in this area has focussed on long-term stable OST patients who have been engaged with OST on a continuous basis. Furthermore, it has been largely quantitative in focus and has tended to concentrate on outcomes achieved by patients with predefined characteristics (such as use of heroin when engaged with OST) (Metrebrian et al., 2015). The quantitative focus of previous research means that prior to this study, relatively little was known about the barriers faced by the long-

term OST population and how these barriers impact on patients and prevent them from gaining benefit from treatment. Similarly, the focus of previous research on OST patients who have been in treatment continuously rather than intermittently meant that little was known about those patients who cycle in and out of treatment services without gaining benefits from OST.

This chapter commences with a summary of the key findings of this project, again using Zinberg's (1984) framework for structural purposes. It reviews the barriers to progress identified by patients and staff and considers how these obstacles might be overcome to improve the health and wellbeing of OST patients. This summary is followed by a brief discussion of the impact of the study on my own personal development. The chapter then moves on to consider the implication of the findings for policy, practice and wider application of Zinberg's (1984) *drug, set and setting* theoretical framework. The chapter concludes with a short discussion on limitations of the study and some recommendations for future research.

## **10.1 Key findings**

It was promising to find that most of the *drug, set and setting* barriers identified by patients and staff, are obstacles that can be overcome. However, this does not mean that the solutions are easy or cheap to implement. Indeed, treatment services will need to consider financial and staffing constraints, when considering the implementation of solutions.

### ***10.1.2 Drug barriers***

The withdrawal phase during titration (the process of induction onto the appropriate dose of substitute medication) and even after stabilisation of medication (fluctuation between withdrawal and stability) was deemed to be a *drug* barrier that could affect the achievement of success from OST. This experience of withdrawal affected the physical wellbeing of OST patients and led in many cases to the continual use of heroin, particularly in the absence of appropriate support (*setting*). OST patients stated that support from GPs (*setting*) is needed to address the barrier of withdrawal during titration. The frequent occurrence of withdrawal symptoms during the window period between opening and closing times of chemists was found to increase the likelihood of the use of heroin. The findings suggested that general health practitioners were reluctant to prescribe pain relief medication to OST patients because they

felt that drug users could not be trusted. The stigma of doctors meant OST patients were not offered external support for alleviation of pain. Similarly, the combination of fluctuation between withdrawal and stability (*drug*) and restricted opening times (*setting*) could have a detrimental impact on the wellbeing of the OST patient. Participants suggested that the provision of take-home supplies of OST could help to address this problem and they noted that it had worked well during the COVID-19 lockdown period. Traditionally, treatment services have been reluctant to trust OST patients with medication because of risks of misuse and diversion. The provision of take-out supplies of OST has been awarded (using contingency management methods) to patients who comply with treatment protocols and provide urine tests that are negative for illegal substances. However, during the COVID-19 pandemic, providing take-outs became a necessity and few problems were noted (Addiction Professionals, 2020). In fact, many positives were noted, including feelings of trust and empowerment. This would tend to suggest that the return to traditional methods of daily pick-ups may not be necessary for all patients.

Another solution for resolving problems with withdrawal, was the wider use of long-acting injectable buprenorphine (a *drug* factor) as a form of OST. The administration of Buvidal was widely acknowledged by patients and staff as an important way of helping patients to manage withdrawal symptoms during the titration phase, because of the absence of withdrawal symptoms after administration of the initial dose. Participants also reported that the administration of Buvidal could help to prevent the withdrawal symptoms that are often experienced by patients prescribed with other types of substitute medication. However, the high cost of Buvidal at £239.70 for a 30-day supply may mean that it is not possible to prescribe this medication to all OST patients (NICE, 2020). This suggested that general health practitioners may need to be more involved in the care of OST patients, especially during the titration phase.

While Buvidal was heralded by many as a positive game-changer, its effects of were also considered by some to be a *drug* barrier that could have a detrimental impact on the achievement of success in OST. For some patients, the blocking effects of Buvidal (*drug*) often meant that heroin was no longer used by OST patients. However, the clarity of mind that is associated with abstinence from heroin (*drug*), was noted to result in the flooding of uncomfortable emotions, which in turn led some patients to start using heroin again to help

them cope. This negative outcome was attributed by some to the absence of counselling services on site and long waiting lists for external counselling (*setting*). Indeed, one staff member suggested that the provision of in-house counselling (*setting*) would be beneficial for all OST patients who needed psychosocial support. However, another participant stated that the co-location of services (and the provision of support in one designated space rather than more widely in the community) could strengthen dependency on drug treatment services. The co-location of services could also mean that OST patients have to attend the same location as others from their drug using circle, which in turn might threaten their recovery.

Another *drug* related barrier identified by participants was the continual use of heroin by OST patients to either alleviate emotional pain or for pleasure. As noted by one OST patient, continuing to prescribe OST while patients are using heroin ‘on top’ puts patients at an increased risk of overdose. Interestingly, there were conflicting perspectives on how this use of heroin should be addressed by treatment services. One perspective was that non-punitive approaches should be used to address the reasons for drug use and treatment services should provide harm reduction measures such as provision of safe injecting information, prescription of pharmaceutical heroin and the use of safe consumption rooms (*setting*). The conflicting perspective was that treatment services should respond with punitive approaches such as detoxification from treatment services, because the substitute medication is no longer of any benefit to the OST patient (*setting*). However, detoxification was perceived by some participants to be related with reversal of progress in treatment and a key factor in propelling the revolving door of OST patients who are cycling in and out of treatment services without making any gains from treatment. The conflicting perspectives on whether treatment services should adopt punitive or non-punitive approaches reflect to some extension the ongoing debates in the field about the purpose of OST. Is the aim of OST to provide patients with stability in their lives or is the aim to help patients achieve abstinence from the use of heroin and opioid substitutes? If harm reduction is at the core of policy and practice in Wales, then exiting patients from treatment seems like a strange option (but perhaps motivated by cost savings). It might be more helpful and potentially more cost effective to work with patients to understand their motives for using heroin ‘on top’ and to find solutions that will help them progress in treatment. This solution is also evidenced by my findings which emphasised the importance of a) addressing the reasons for heroin use and b) premature exits from treatment

strengthened the ‘revolving door’ where OST patients cycled in and out of treatment services without making any gains from treatment.

Interestingly, some participants identified the quality of heroin as a *drug* barrier that could affect the achievement of success from OST. Participants explained that the low quality of heroin (*drug*) could mean that increased quantities are needed to alleviate withdrawal symptoms (e.g. during the titration phase), which in turn increases financial pressure. For some patients, this increased financial pressure increased their likelihood of offending and/or engaging in sex work. By contrast, some participants explained that the low quality of heroin led to the cessation of use, because using weak heroin was pointless. The conflicting views on this (and other issues) highlights that the barriers for OST patients are very much **individualised**.

While poor quality (weak) heroin created its own problems, participants also noted that higher quality (strong) heroin was also felt to be problematic. It was perceived to be a *drug* barrier because strong heroin can increase tolerance levels and reduce the efficacy of substitute medication. As a solution, participants recognised that staff members need to spend more time with OST patients to fully understand the influence of any factors that could impede progress in treatment. However, time and financial constraints could mean that staff members do not always have the necessary time to spend with OST patients (*setting*). However, Dame Carol Black’s (2021) review showed that £1 investment in drug treatment services could result in £4 savings in health, prison, law enforcement and emergency services. This suggested that the potential cost savings to society could far outweigh these costs.

### ***10.1.3 Set barriers***

Many OST patients described having low confidence (*set*) in their ability to achieve success from OST and this was often linked to their long histories of drug use and adverse childhood experiences. More time in treatment (*setting*) was perceived to be a solution that could address these issues. Increasing the visibility of success in treatment (*setting*) was identified as an important way of helping patients to boost their confidence and accept that success was a real possibility for them and people like them. Similarly, painting a personalised visualisation of

abstinence with each OST patient (*setting*), was suggested as a way of promoting the achievability of abstinence, thereby improving confidence levels and promoting progression in treatment.

Another *set* barrier identified by participants as an obstacle to progress was that mistrust in the efficacy of OST. Previous negative treatment experiences (*set*) (e.g., that involved inaction upon disclosure of mental health issues or poor therapeutic relationships), resulted in some OST patients failing to share information with staff members in subsequent treatment episodes. Of particular concern was the inability of some staff members to respond to and address mental health issues disclosed by patients. This was identified as a particular problem in relation to the flooding of emotions that cessation of heroin use created for some patients, particularly those on Buprenorphine. The training of staff members to respond to mental health issues in an appropriate manner was identified as an important way of helping to enhance trust levels and promote progression in treatment.

The inconsistency in the delivery of psychosocial interventions also contributed to mistrust in the efficacy of treatment services. There was no consensus among participants (staff and patients) on whether the use of evidenced based psychosocial interventions or informal approaches are more effective in the facilitation of treatment success. The adoption of an individualised approach by matching the specific needs of the OST patients to the appropriate keyworker was identified as a useful way of helping to improve trust levels. The lack of visibility of successes (*setting*) within treatment services also contributed to low trust levels (*set*) and subsequently impeded progression in treatment and, for some, resulted in stagnation. Participants stated that the visibility of treatment successes within treatment services could be enhanced through employment of people with lived experience.

Perhaps as a result of their mistrust in services, many OST patients expressed anxiety of losing their substitute medication (*set*). For some, this resulted in the use of dishonesty to retain medication. In other words, patients lied about their use of heroin ‘on top’ of OST. This dishonesty created an illusion that treatment was working when the OST patient was, in fact, struggling to make progress. This fear of losing medication appeared in some cases to be related

to the practice of discharging patients caught using ‘on top’ early from treatment services on the grounds that using ‘on top’ increases the risk of opioid overdose. However, some participants thought that this apparently ‘punitive’ approach was inappropriate and meant that opportunities to help patients make progress in treatment were lost. For instance, openness is needed for a successful therapeutic relationship and achievement of benefits from OST. Ideally, treatment services should facilitate an atmosphere where OST patients can be open about their use of heroin. This is important because harm reduction is at the heart of Welsh drug policies. However, the issue surrounding the risks of using heroin with substitute medication remains. An alternative approach suggested by some participants was that treatment services should encourage honesty by assuring patients that they will not lose their medication (*setting*) except in circumstances where they were caught selling or diverting their substitute medication. While this solution is clearly an attractive one, in some respects it is a risky one that may not be acceptable to prescribers who would need to prescribe opioid substitutes to someone who they know is also using heroin. That said, it is highly likely that patients are using on top during the titration phase (as shown by my findings). It was also suggested that staff work closely with patients to explore their motivations for using ‘on top’ and help them to stop. The solutions of prescription of heroin and the use of harm reduction approaches (as stated by the participants) could also help with the facilitation of a treatment setting that encourages openness about the use of heroin.

Being ‘unready’ to change was also identified as a *set* barrier that had an adverse impact on the efficacy of treatment. The use of pressure by treatment services (*setting*) in response to ‘unreadiness’ was reported to increase the consumption of heroin among some patients. Therefore, instead of trying to ‘force’ the onset of readiness, it was suggested that treatment services should deliver interventions aimed at increasing the accumulation of recovery capital (*setting*) that would help people to achieve their treatment goals. Another solution that emerged from the research was the concept of a two-tier treatment system (abstinence and harm reduction) based on patients’ ‘readiness’ to stop the use of heroin (*setting*). This system appears to be initially more costly, as it involves the provision of support to people who are not ready to stop their use of heroin. However, this two-tier system would provide patients who were not yet ready to change with the support and help that could increase motivational levels to stop the use of heroin. In fact, a staff member in my study stated that he worked on accumulation of recovery capital when OST patients were not ready to stop their use of heroin. The staff

member explained that this accumulation of recovery capital had increased stability in his life, which could in turn increase motivation to stop the use of heroin. Therefore, the two-tier system could help with the achievement of treatment goals and lead to cost savings more broadly (e.g., in terms of a reduction in crime).

Feelings of shame following a lapse or relapse were described by some patients as a key barrier that affected progression in treatment. These feelings led some patients to drop out of treatment and prevented others from returning. Sadly, it emerged that even previously strong relationships with staff members were insufficient to address the barrier of shame. Therefore, it was suggested that treatment services need an ‘open door’ policy approach, which emphasises that OST patients are welcome to return to treatment services if they need to do so (*setting*) without fear of judgement or rejection. In fact, in some cases the stronger the relationship with their key worker, the more shame the patient felt.

#### ***10.1.4 Setting barriers***

KPI five emphasises that treatment services must have an “increased number of ‘treatment completed’ closures” (Welsh Government, 2021, p.11). According to the KPI, “treatment completed will be deemed as either problematic substance free or by client reaching treatment goal(s) as agreed at the commencement of treatment” (Welsh Government 2021, p.10). This suggests that WG is encouraging both the completion of treatment and achievement of abstinence.

The findings suggested that there is a cohort of long-term OST patients who are cycling in and out of treatment services without achieving any benefits from treatment. The findings suggested that there are many reasons why this cohort of long-term OST patients are not achieving benefit from treatment services. One reason was that all OST patients who entered treatment services were not ready to stop their use of heroin. Staff members were also aware that some OST patients are not ready or cannot stop their use of heroin. However, the operation of treatment services is very much geared towards the achievement of abstinence. This is evidenced by the use of rapid detoxifications in response to the use of heroin and taking away of privileges in response to positive drug test results.

The rationale behind the use of these punitive approaches was concerns around risks of overdose that is associated with the use of substitute medication with illicit heroin. Further research should investigate how treatment services can support OST patients who are not ready/cannot stop their use of heroin in a clinically safe way. One solution identified by participants was to prescribe pharmaceutical heroin to OST patients and deliver harm reduction approaches to the cohort of OST patients who are not ready to stop their use of heroin. This solution is advantageous because it allows OST patients to be open about their drug use and harms are also minimised. Participants in the study also recognised that a cohort of OST patients may need long term maintenance of substitute medication in order to continue to achieve benefits from OST. This suggested that treatment services may need to carefully differentiate between OST patients who need maintenance with those who want to reduce their substitute medication.

Attendance is not always a reliable indicator of success in treatment and not all OST patients are capable of attending appointments due to their chaotic lifestyles, which often includes being homeless. One solution recommended by participants was the use of assertive outreach programmes and informal support systems (*setting*) to meet the needs of OST patients who are unable to attend their appointments. It is noteworthy that the drug agency runs an assertive outreach scheme which has worked well in bringing back patients who have dropped out of treatment back into the fold. While this kind of approach requires a significant investment and recruitment of appropriate staff members the benefits are clear and could result in cost savings further down the line (e.g., in terms of healthcare savings).

The focus of treatment services on the importance of medication has resulted in the reluctance of some OST patients to work towards progressing in treatment. The focus on medication has also meant that OST patients attributed achievement of successes in treatment to the medication, as opposed to their own determination and hard work. Possible solutions that emerged from the research include the exploration of non-medical options (e.g. other psychosocial interventions) and interventions that help with reduction of heroin prior to prescription of substitute medication. This reduction of heroin could help to convey the message that work is needed for the achievement of success in treatment. Provision of

diversionary activities to help patients build recovery capital could help to minimise the importance of medication and promote progress in treatment (*setting*).

Participants in this study reported that services often fail to address the trauma associated with adverse childhood experiences in an appropriate manner. The impact of trauma on treatment progress was raised as a particular problem associated with the administration of Buvidal (*drug*), which blocks the effects of heroin and can result in a flooding of emotions. To some extent, the failure of services to respond appropriately to trauma has propelled the ‘revolving door’ of OST patients in and out of treatment. An obvious solution to this would therefore be to ensure that drug workers are sufficiently well trained to provide this support or to ensure that specialist trauma services are available for patients who need them.

Treatment was also perceived to interfere with family life, the planning of holidays and employment. The monthly injection of Buvidal (*drug*) was deemed to minimise interference, while simultaneously eliminating the risks of misuse and diversion. However, while there were clear positives associated with the administration of Buvidal, concerns were also noted. The main problem acknowledged by participants was the reduced contact between patients and staff (monthly rather than weekly or daily) and the limited opportunities this afforded for assessing and monitoring non-drug related risks (e.g. domestic violence, broader health issues). One possible solution might be for key workers to ‘check-in’ with Buvidal patients on a weekly basis by phone. This would not allow staff to assess visually the patient’s health and vulnerability, but it would provide an opportunity for a verbal discussion during which patients could divulge any issues with their key worker. Another solution could be to refer Buvidal OST patients to non-drug support services. This could mean that non-drug related issues are addressed, and the OST patient is also distanced from the influence of the drug using network within treatment services.

While irregular contact with services clearly has its drawbacks, participants also described some benefits. As well as providing greater opportunities for family holidays and employment, attending services infrequently meant that patients had far less contact with their drug-using networks. This subsequently reduced the temptation to use heroin or sell their medication. For

those on daily pick-ups, it was suggested that seeing OST patients on a 'one in, one out' basis (a system adopted successfully during the COVID-19 lockdowns) could help to minimise the contact with their drug-using networks (*setting*). The main drawbacks of this approach are that it may be time-consuming to accommodate one patient at a time and difficult to enforce if patients are agitated and suffering from painful withdrawal symptoms (e.g., during the titration period). Furthermore, patients may well congregate outside the service, which would negate the benefits of the 'one in, one out' system. However, the positive experiences reported during the pandemic tends to suggest that the benefits of this approach far outweigh the costs.

For some patients, being on the waiting list for substitute medication was associated with suicidal feelings, financial struggles, entrenchment of drug use and offending behaviour. Participants stated that rapid access to substitute medication is needed to alleviate the immense difficulties associated with the *setting* barrier of the waiting list. The evaluation of the Medway rapid prescribing service in Medway showed that rapid prescribing required both high levels of staffing and high financial expenditure (Klein and Oshowale, 2007). However, the rapid prescribing was associated with significant benefits such as reduced illicit drug use, reduced offending behaviour and social stability. This suggested that the initial expenditure could be offset by savings to the health service and criminal justice system. Furthermore, the evaluation of the Medway project identified the importance of continuity of care and strong therapeutic relationships in the achievement of benefits from OST. This implied that treatment services must ensure that rapid prescribing services are accompanied by the delivery of appropriate psychosocial interventions.

Interestingly, participants reported conflicting views on the value of 'lived experience' in the provision of OST. The diverging views presented on this, support the call for an individualised approach that meets the specific needs of OST patients. For example, a key worker with their own history of OST may be a positive influence for some patients but their success may be viewed less positively (e.g., jealously) by others. A careful matching process where the needs and values of patients are matched with appropriate staff could help with this to some extent.

Some participants noted that a lack of recovery capital in the OST patient's life even after achievement of abstinence could impede their progression in treatment. Events such as the 'Hot Dog Mornings' (where free food is provided to patients within services) were identified as a potentially powerful way of enhancing recovery capital (for example OST patients mutually supported each other to attend the gym) and promoting progression in treatment. Treatment services have unwittingly strengthened stigma against people who use drugs by failing to provide opportunities for reintegration and the provision of activities that centre around drug treatment services.

## **10.2 Impact on researcher's personal development**

Summarising the key findings of my research has provided a useful opportunity to reflect on my own personal development over the course of my PhD studies. Upon reflection, this study has benefited me both on an academic and personal level in many ways. As touched upon in previous chapters, my previous role as an 'active treatment worker' involved delivering psychosocial interventions to OST patients. Conducting this study meant that I returned to the same drug agency with a different 'hat'. This new role of being a 'researcher' was illuminating to me on a personal level, as it enabled the observation of barriers faced by both OST patients and staff members from a different and distanced perspective. For example, I saw the 'busyness' of the treatment service with fresh eyes as a potential barrier, whereas before in my previous role I had accepted the 'busyness' as a given norm of working in a drug treatment agency.

A key benefit of my previous role as 'active treatment worker' was that it helped me to develop a rapport with participants within a short space of time. Additionally, I noticed that my role as a researcher and subsequent distance from the drug agency allowed OST patients to be more open both on what is working in treatment services and also what is not working so well. The interviews gave a harrowing insight into some of the issues faced by OST patients such as abuse, financial difficulties, homelessness loneliness which are often misunderstood by society (just to mention a few). Many OST patients stated that society had negative stereotypical views of people who use drugs, which meant that members of the public were not aware of their true personalities. Many OST patients also said that they experienced stigma on a regular basis. However, it was not all negative as all of the OST patients in the study also showed intelligence,

sense of humour, insight, determination and strength during the study, sometimes in the face of extreme adversity. These strengths were a source of powerful inspiration for me on a personal level.

The use of co-production helped me to develop as a researcher and person in numerous ways. The co-production powerfully highlighted the invaluable expertise of OST patients in the development of research projects, such as support in drafting the interview schedule, determination of the sequential order of interviewing participants, rewards for participation, and the benefits of providing snacks. From a professional perspective, my research experience helped me to develop new working relationships with people with lived experience and also with new staff members. The study also helped me build on existing working relationships with members of staff at the drug agency.

As explained in the methodology chapter, the COVID-19 restrictions meant that I was unable to continue with my field work and ethnography. However, upon reflection, the restrictions provided me with the opportunity to both increase my resilience and creativity. For example, I had to think of new ways in which participants could be accessed while complying with COVID-19 restrictions. Interviewing participants during the COVID-19 pandemic also gave me a unique perspective of Buprenorphine as both a barrier and facilitator of treatment success. It is important to note that few studies have investigated the impact of Buprenorphine and the timing of this study (which coincided with the pandemic when Buprenorphine was introduced across Wales) provided a great opportunity to help fill this gap in knowledge. The interviews also helped to elicit how beneficial practices adopted during the pandemic could be used in the future.

During the study, I also delivered seminars on 'substance misuse'. Hopefully, both my research and previous experience as active treatment worker contributed to the facilitation of engaging and lively discussions with students. The support from other research students was invaluable and extremely beneficial during every stage of the study. Interestingly, this tallied well with one of my findings, which noted that it is sometimes helpful to have the support of someone who is facing similar issues. On a personal level, one of the participants and my ex-client sadly passed away during the study. This powerfully and emotionally brought home to me that there

are lives behind the statistics on drug-related deaths and that finding ways of improving the outcomes patients in OST is needed if lives are going to be saved.

### **10.3 Implications for policy and practice**

This research study focused on improving the health and wellbeing of OST patients who are struggling to achieve benefits from OST, despite long term engagement with services. Therefore, the study clearly has implications for the delivery of OST within drug treatment services. However, the findings also have implications for drug policy, drug legislation, criminal justice interventions and harm reduction.

#### ***10.3.1 Implications for delivery of OST***

Many OST patients stated that factors such as quality of illegal drugs (e.g. heroin) and histories of abuse affected the achievement of benefits from OST. An important implication is that staff members need to spend more time with OST patients to facilitate the identification of factors that could impede progress in treatment. However, the ‘busyness’ of the treatment services and requirements of paperwork were all observed to reduce the amount of time available to spend with OST patients. Dame Carol Black (2021) recommended the recruitment of more specialist staff members within treatment services, especially given the finding that many existing staff members have extremely high caseloads of clients. The recruitment of more staff members could increase time resources and improve the quality of care that is offered to OST patients (Dame Carol Black, 2021). The discussion on Buvidal suggests that staff members should be adequately trained to meet the complex needs of OST patients and be able to provide specialist trauma counselling for patients in need of this kind of support. Alternatively, access to this kind of support must be available to those in need quickly and efficiently. Matching the OST patient to the appropriate staff member at the commencement of the treatment episode could also help with rapid establishment of trust. This could increase time resources for the staff member to get to know the OST patient and contribute to progression in treatment. The greater involvement of GPs (e.g., through Shared Care programmes) and external support services in the care of OST patients could also help to reduce pressure on drug treatment services.

The monthly administration of Buprenorphine was perceived to address multiple barriers such as stigma, withdrawal during titration and treatment's interference with lifestyle (i.e., holidays, employment). This is because the injection method removes the risks of misuse and diversion, which means that OST patients could be given more freedom and flexibility. Yet, there were concerns that the monthly administration of Buprenorphine may mean that non-drug related risks of OST patients cannot be monitored. One important implication is that despite the immense benefits of Buprenorphine, treatment services need to be cautious that medication is not given undue emphasis.

The findings suggest that some OST patients may be unable to meet the expectations of treatment services. If OST patients are unable to achieve abstinence, treatment services may need to explore other approaches such as harm reduction interventions. Some OST patients may also be incapable of attendance at appointments (that is required by treatment services) because of their chaotic lifestyles. For this cohort of OST patients, specialist interventions such as assertive outreach, informal support, and staff with 'lived experience' of OST, may be needed to promote progression in treatment. This again highlights the importance of an individualised approach to meet the specific needs of OST patients.

The findings also suggest that OST patients could be differentiated on the basis of their readiness to stop the use of heroin. Participants suggested that those who are not ready to stop their use of heroin should be offered harm reduction interventions, while those who are ready to stop the use of heroin should be offered an ambitious recovery-focused strand of treatment. This individualised approach could also help to build rapport and trust and subsequently help to reduce dishonesty within the therapeutic relationship.

The findings suggest that treatment services do not provide enough opportunities for reintegration with society because of fear that OST patients will be stigmatised in mainstream society. Yet, this practice has strengthened stigma against OST patients and prevented OST patients from moving forward in treatment. Similar to Best (2019), one perspective of participants was that recovery capital could be enhanced through development of opportunities for reintegration. This could challenge stigma and increase availability of resources to OST

patients, which could enhance accessibility to external support (Best, 2019). The achievement of reintegration and development of partnerships with the community could also increase visibility of successes within treatment services, increase trust levels in efficacy of treatment services and promote progression in treatment.

### ***10.3.2 Implications for harm reduction***

There was clear tension within the findings on whether treatment services should use punitive or non-punitive approaches to improve the wellbeing of the OST population. Ironically, the use of punitive approaches that are intended to minimise harm, were found to be counterproductive and increased harm to some OST patients. One important implication is that treatment services need to foster an environment where OST patients can be open about their use of heroin. The introduction of a two-tiered treatment system (that includes a harm reduction and an ambitious recovery-focused strand) based on the patient's readiness to change could help to increase openness of OST patients and minimise harm to OST patients.

During the interviews, participants referred to long waiting lists for OST and lost opportunities to enroll motivated patients into OST. Making patients wait for treatment meant that some reached the top of the list and entered treatment at a time when their motivation to change had decreased. The implication of this is that patients need to be offered rapid access to treatment to ensure that the benefits of substitute medications are realised as soon as possible. Alternatively, services might benefit from assessing patients' motivation levels on entry into treatment and direct them accordingly to either the harm reduction strand or the recovery-focused strand of the two-tier treatment system outline above.

### ***10.3.4 Implications for drug policy and legislation***

Some participants noted that there was a focus on achieving abstinence from heroin use and this was linked, in part, to the importance of meeting Key Performance Indicator 5, which promotes treatment completion and abstinence. However, it was recognised that these are not appropriate goals for all OST patients and that positive outcomes can still be achieved by patients who remain in treatment and even for those who continue to use heroin. Services would

benefit from clearer guidance from the Welsh Government on whether indefinite maintenance on substitute medication amounts to success in treatment.

Participants stated that the prescription of pharmaceutical heroin (diamorphine) would be appropriate for those who continue to use illegal heroin for reasons such as bereavement or the alleviation of emotional pain. In order to prescribe heroin today, doctors need a Home Office Licence under the Misuse of Drugs (Supply to Addicts) Regulations 1997 (UK Government, 2020). However pharmaceutical heroin is prescribed to only a small cohort of opioid dependent patients who have not previously benefitted from OST (Klous et al. 2005). Doctors reported that they did not prescribe heroin because of the absence of appropriate training, high cost, inadequate facilities and lack of evidence for efficacy of interventions (Metrebian et al. 2002). The main implication of this is that more training for doctors is needed and that more funding is needed to both increase access to heroin assisted treatment and to support evaluations of its efficacy.

#### ***10.3.5 Implications for methodology and theory***

Zinberg's *drug, set and setting* framework (1984) was beneficial in helping to understand both the barriers faced by the long-term OST population in achieving success from OST and the elicitation of solutions that could help to address these barriers. Zinberg's (1984) framework also aided the understanding of how *drug, set and setting* barriers interact in complex ways to affect the wellbeing of the OST patient. For example, the effects of Buvidal (*drug*) was found to lead to enforced abstinence, which in turn resulted in flooding of emotions (*set*). This flooding of emotions (*set*) then became a barrier in the absence in the absence of appropriate support (*setting*).

However during the write stage up of my results, I recognised ways in which Zinberg's (1984) *drug, set and setting* framework could be further enhanced. When analysing the data I realised that the *drug* factors of effects of illicit drugs and effects of substitute medication are quite different. For instance, the effects of illicit drugs are associated with different issues such as illegality, quality of the drug, and financial cost. The effects of substitute medication, however, are associated with issues such as dispensing practices. It might therefore be helpful to have

subcategories within the *drug* factors category such as illicit drugs and prescribed drugs. Similarly, in relation to the *setting* it became clear that the situation in which people use drugs is quite different to the setting in which they ‘use’ substitute medication. Adapting the framework to accommodate these differences may therefore be a useful way forward for studies investigating treatment experiences.

Like other researchers, when analysing the results, I noticed that the boundaries of *drug*, *set* and *setting* factors became blurred (Lamonica et al., 2021). In these circumstances, I carefully tried to ascertain which of these factors affected the wellbeing of the OST patient. Therefore, researchers need to clearly guide readers as to which factor is most directly related to the issue in question.

#### **10.4 Limitations of the study**

While the study has many strengths including its qualitative focus and exploration of different perspectives faced by the long-term OST population, it also has a number of weaknesses that must be acknowledged when reflecting on the conclusions. An important limitation is the opportunistic sampling approach and relatively small number of participants recruited from one drug service (albeit a busy one covering rural and urban locations), which means that the findings cannot be generalised to the wider drug-using population (Neale, Allen and Coombs, 2005). This means that the findings may only be applicable to the particular drug agency in South Wales, where the research was conducted.

There may also be an element of sampling bias as participants may have been more likely to approach me if they felt that they were benefitting from treatment in some way. This could mean that potentially there is an underrepresentation of OST patients who do not perceive themselves to be benefitting from treatment (Meyer and Wilson, 2009).

It is also important to note that the accuracy of the responses in the interview could have been adversely affected by a reduced ability to remember emotions and events, which is a particular problem for the drug-using population (Neale et al. 2005). However, the interview questions

were based on current and/or recent treatment experiences for many of the long-term OST participants. The participants who had finished treatment a long time ago were still able to reflect on current strategies they used to maintain the positive changes that they had made. My previous acquaintance with some of the participants during my role as active treatment worker and fieldwork at the venues in varying capacities contributed to the development of rapport with the participants, which could have enhanced accuracy of responses (Neale et al. 2005).

Lastly, due to the COVID-19 pandemic I had to suspend interviews with staff members and clients who were involved with IRIS (the criminal justice arm of the drug agency) and fieldwork in other venues of the drug agencies. This could have reduced the representativeness of OST patients who have current involvement with the criminal justice system and affected the recruitment of participants from diverse geographical areas. However, I tried to enhance diversity by approaching long-term OST patients from diverse areas as much as possible via the telephone.

### **10.5 Future recommendations for research**

This qualitative study has helped to fill an important gap in knowledge by identifying the barriers faced by the long-term OST population. It has also identified ways in which these barriers could be addressed in South Wales. These goals were achieved through (a) in-depth interviews with both OST patients and staff members who have first-hand experience of the issues, and (b) a ‘microethnography’ of drug treatment services in South Wales that included informal visits to the various sites in which the drug service operates.

One important finding that emerged from the research was the lack of clarity surrounding how physical and mental health issues of OST patients should be addressed. OST patients communicated that the stigmatised views held by some doctors and long waiting lists for treatment meant that these important physical and mental health issues, were not addressed which in turn impeded progress in treatment. Therefore, future research should focus on the exploration of how treatment services could improve treatment for non-drug related issues too.

There were conflicting perspectives regarding the ‘vulnerability’ of OST patients. For instance, there were concerns that a history of ACEs could mean that some OST patients are not capable of achieving abstinence. Similarly, participants highlighted that some OST patients are unable to attend appointments for a variety of reasons such as homelessness. Participants stated that OST patients sometimes expressed anger and frustration because of their vulnerability. Future research should therefore be directed to explore how treatment services could accommodate this vulnerability, to promote progression in treatment.

There was also limited clarity on whether the failure to achieve benefits from OST could be attributed to therapeutic nihilism of staff members i.e., a) the lack of belief of staff members that OST patients can change or b) the failure of treatment services to consider factors such as ACEs in the delivery of treatment. Further research is needed to determine the role of these factors in non-achievement of benefits in OST and how treatment services could address these factors to facilitate achievement of benefits from OST.

### **Concluding comment**

This study provides a unique contribution to knowledge through its: novel application of Zinberg’s (1984) framework, focus on Wales, inclusion of staff and patients, inclusion of patients on different kinds of OST including injectable buprenorphine, and the inclusion of patients who have been on OST intermittently or continuously over a five-year period.

This study examined the *drug, set* and *setting*-related barriers to progress faced by the long-term OST population and identified a range of solutions that could help improve their health and social outcomes. The research is important and timely given that drug-related deaths are at record high levels across the UK. The research identified conflicting perspectives on how to address the obstacles faced by long-term OST patients. These conflicts were due, in part, to the competing needs of services to provide accessible services, to meet KPIs, to support reintegration, keep patients safe and the need to convey a sense of understanding to the OST patient. Improving the outcomes of patients on long-term OST is an important topic for many reasons, not least because it could help to save lives.

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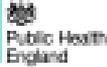
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# Appendices

## Appendix 1 -Treatment Outcome Profile



### TREATMENT OUTCOMES PROFILE

<p><b>CLIENT ID</b></p> <input style="width: 100%; height: 20px;" type="text"/>	<p><b>KEYWORKER</b></p> <input style="width: 100%; height: 20px;" type="text"/>
<p><b>GENDER</b></p> <p>MALE <input type="checkbox"/> FEMALE <input type="checkbox"/></p>	<p><b>TREATMENT STAGE</b></p> <p>START <input type="checkbox"/> REVIEW <input type="checkbox"/> EXIT <input type="checkbox"/> POST-TREATMENT <input type="checkbox"/></p>
<p><b>DOB</b></p> <input style="width: 100%; height: 20px;" type="text"/>	<p><b>INTERVIEW DATE</b></p> <input style="width: 100%; height: 20px;" type="text"/>

USE 'NA' ONLY IF THE CLIENT DOES NOT DISCLOSE INFORMATION OR DOES NOT ANSWER

### 1 SUBSTANCE USE Total for NDTMS return

	WEEK 4	WEEK 3	WEEK 2	WEEK 1	AVERAGE PER DAY	
A. ALCOHOL <small>Record the number of using days in each of the past four weeks, and the average amount used on a using day</small>	<input type="text"/>					
B. OPIATES/OPIOIDS (ILLICIT) <small>Includes street heroin and any non-prescribed opiate, such as methadone and buprenorphine</small>	<input type="text"/>					
C. CRACK	<input type="text"/>					
D. COCAINE	<input type="text"/>					
E. AMPHETAMINES	<input type="text"/>					
F. CANNABIS	<input type="text"/>					
G. OTHER SUBSTANCE SPECIFY:	<input type="text"/>					

### 2 INJECTING RISK BEHAVIOUR

	WEEK 4	WEEK 3	WEEK 2	WEEK 1	
A. INJECTED <small>Record the number of days (not necessarily consecutive) you presented drugs during the past four weeks</small>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
B. INJECTED WITH A NEEDLE OR SYRINGE USED BY SOMEBODY ELSE	YES <input type="checkbox"/>	NO <input type="checkbox"/>			<input type="text"/>
C. INJECTED USING A SPOON, WATER OR FILTER USED BY SOMEBODY ELSE	YES <input type="checkbox"/>	NO <input type="checkbox"/>			<input type="text"/>

### 3 CRIME

	WEEK 4	WEEK 3	WEEK 2	WEEK 1	
A. SHOPLIFTING <small>Record the number of days of shoplifting, drug selling and other categories committed during the past four weeks</small>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
B. SELLING DRUGS	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
C. THEFT FROM OR OF A VEHICLE	YES <input type="checkbox"/>	NO <input type="checkbox"/>			<input type="text"/>
D. OTHER PROPERTY THEFT OR BURGLARY	YES <input type="checkbox"/>	NO <input type="checkbox"/>			<input type="text"/>
E. FRAUD, FORGERY OR HANDLING STOLEN GOODS	YES <input type="checkbox"/>	NO <input type="checkbox"/>			<input type="text"/>
F. COMMITTING ASSAULT OR VIOLENCE	YES <input type="checkbox"/>	NO <input type="checkbox"/>			<input type="text"/>

### 4 HEALTH & SOCIAL FUNCTIONING

<p>A. CLIENT'S RATING: PSYCHOLOGICAL HEALTH <small>(Anxiety, depression, problem emotions and feelings)</small></p>	<p>0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20</p> <p>POOR <span style="float: right;">GOOD</span></p>	
B. DAYS IN PAID WORK <small>Record days worked, on at college or school in the past four weeks</small>	<p>WEEK 4 <input type="text"/></p> <p>WEEK 3 <input type="text"/></p> <p>WEEK 2 <input type="text"/></p> <p>WEEK 1 <input type="text"/></p>	<input type="text"/>
C. DAYS ATTENDED COLLEGE OR SCHOOL	<p>WEEK 4 <input type="text"/></p> <p>WEEK 3 <input type="text"/></p> <p>WEEK 2 <input type="text"/></p> <p>WEEK 1 <input type="text"/></p>	<input type="text"/>
D. CLIENT'S RATING: PHYSICAL HEALTH <small>(Extent of physical symptoms and bothered by them)</small>	<p>0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20</p> <p>POOR <span style="float: right;">GOOD</span></p>	<input type="text"/>
E. ACUTE HOUSING PROBLEM	YES <input type="checkbox"/> NO <input type="checkbox"/>	<input type="text"/>
F. AT RISK OF EVICTION	YES <input type="checkbox"/> NO <input type="checkbox"/>	<input type="text"/>
G. CLIENT'S RATING: OVERALL QUALITY OF LIFE <small>(Able to enjoy life, gets on with family and partners, etc)</small>	<p>0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20</p> <p>POOR <span style="float: right;">GOOD</span></p>	<input type="text"/>

## **Appendix 2 - Schedule for interview with the long-term OST population**

### **Introduction**

Brief description of project and aims  
Ethic approval obtained from USW  
Consent form  
Anonymity and boundaries of confidentiality  
Permission to record interview  
Opportunity to ask questions of what will be involved.  
How are you?

### **Characteristics of the population**

Tell me a little bit about yourself.

Thank you so much for agreeing to take part in this research. Please could you tell me a little about the reasons why you said that you would be interviewed. When I say interview, I mean an informal discussion about what you feel is working well for you in treatment and what could be done better.

Thinking about our discussion that ‘not currently benefiting from treatment’ means different things to different people, how would you describe yourself and why? (Probes on if and why they identify themselves as not currently benefiting from treatment and if their personal view of ‘not currently benefiting from treatment’ is different to that of treatment providers)

### **Prior treatment episodes**

What does the word treatment mean to you?

Please could you tell me a little bit about when you first started using heroin and what happened for you to start treatment?

Please could you now tell me about your treatment journey since the first time you started treatment to where you are now? (General exploration of treatment journey; How many types of treatment? Probes on types of treatment and if they all ended the same way?)

### **Current treatment: practice in delivery/ receipt of treatment**

I'd like to ask you now about the service that you are working with now.

Have you had treatment with them before? If yes, what was it like walking through the door to start treatment again knowing that you have been with them before? (Probes on feelings, how are you treated by staff, elicit positives and negatives and its relation to achievement of goals).

It would be really helpful for me to get an idea of what your life in treatment is like. Please can you tell me in as much detail as possible i.e. what normally happens from referral to when you are in treatment? (prompt for dose, take-outs, how long, supervised, how meds are taken and where, weekends, holidays, experiences of going up and down on medication, treatment contract is the dose optimal, what happens if you use heroin, what happens in appointments, how often are you seen by staff, details of any testing).

What normally happens from when you wake up in the morning to when you go at bed at night? (could help to elicit feelings of boredom, loneliness, social circle, housing, diet, finances, pain, hobbies or lack of hobbies, heroin use, stigma (how other people view those who are on long term scripts- use further questions to probe about how this is affecting progress in treatment?).

**Current treatment: relationships and goals**

Different people want different things out of treatment. Try to imagine that you have achieved everything that you wanted to get out of treatment. What would life look then? What does success in treatment mean to you? (probe in depth for comments about different outcomes, e.g. health, housing, finances, relationships, safety, security, happiness, being listened to, friendships, confidence, pursue hobbies, anything important to them.)

What do you think that staff want you to get from your treatment? (Probe for their understanding of what providers wants from them, e.g. improvements in health, employment, offending, relationships; how is this different to your definition?).

Please tell me about how you get on with your a) keyworker b) doctor and c) nurse (prompts about if they have supported you in goals of treatment, what has been good/ bad, what worked really well and why?)

**Current treatment: outcomes (include issues relating to drug, set and setting approach)**

What are the benefits to being in treatment for you?

You said that doing well in treatment means.... (Reflect previous responses)

How well do you think you are doing in treatment at the moment? (Probe for details on achievement of goals and reasons why and what goals are not being achieved and why not from a treatment perspective; also how well do staff think you are doing in treatment (On a scale from 1 to 10, how well do you think you are doing in treatment (1 = not at all well and 10 being extremely well – couldn't do any better!)

How strongly do you believe that you will achieve what you want from treatment? (Prompts in confidence and also what is it about treatment that is affecting your confidence?)

If it's ok I would like to understand more about the things that is stopping you from getting to where you want to be.

Thinking about your treatment now, what is wrong with the present system that is stopping you from (reflect participants definition of treatment success) getting to where you want to be? (Probes on medication, going up and down on medication, drug, mindset, take outs, treatment contract, venue, opening times, relationships with staff, what would people important to you say etc.).

Generally, what is it about treatment that is stopping people on long term scripts from moving forward or progressing in treatment?

If your keyworker/doctor/ nurse was in the room now, what would they say are the main things in treatment that are stopping people from moving forward? (Probes on high caseload, not enough time, stress etc.)

*You mentioned earlier on that ‘doing well in treatment’ to you means.... I would now like you to think about other things which have nothing to do with treatment but is stopping you from moving forward (e.g. finances, housing, mental health, relationships with family, what would people important to you say etc.)?*

What is helping you to move forward in treatment to where you want to be? (Probes on relationship with staff, flexibility, activities etc.)

What else is helping you to move forward that might be unrelated to treatment?

### **Previous ‘not so positive’ treatment episodes**

I thought it might be helpful to reflect on your treatment journey, as sometimes barriers to ‘where we want to be’ may change with time. *If your treatment journey was a video and you had to pause at a not so good time, what would that that time look like to you?* What was it about this treatment that made it a ‘not so good experience’? (Probes on if you were achieving your goals or not, reasons why treatment was not going well for you - treatment related factors (dose, location, staff, barriers to success, opening times) or external factors (e.g. family, finance, health) [If not, then move on to a good day].

### **Previous positive treatment episodes**

Could we now pause the video on a time when things were going really well in treatment? Please tell me more about what was happening at the time. (Probes on achievement of goals, treatment related factors that helped (staff, dose, flexibility) and external factors that helped (feelings, social circle, motivation).

### **Turning points**

We have talked about when you were previously struggling in treatment. After your worst treatment episode, please describe the ‘defining moment’ or turning point when you felt things had to change. When I say ‘change’, this could be reducing drug use, abstinence, engaging with treatment services, accessing other support services, or the first step towards success etc. (Elicit information on the turning point- was it thoughts, staff, family, withdrawal, relationship maturing etc).

What motivated you to make the change? (Treatment, personal factors)

What helped you with the change?

What was different about this occasion compared to previous times when you had tried to make changes?

Please describe your journey from that first turning point to where you are now (explore turning points).

What was the initial change period like? (Elicit both pros and cons)

What was it like as time went on?

If you could go back in time what would you tell your former self?

What tips would you give to someone who is struggling in long term treatment?

What tips would you give to staff members?

### **Current life**

Describe what ‘success in treatment’ or ‘success with regards to drugs’ means to you.

Thinking about what you just said about success means to you, what number would you give yourself if 0 was I have not achieved where I want to be and 10 is, I have achieved everything I wanted to (explore reasons for number).

In light of what you just said, how long have you been doing well?

Describe a typical day in your life now from when you wake up in the morning (elicit formation of new relationships, routine activities).

Describe any substances that you use now (elicit type, quantity, frequency etc).

How would you describe yourself now? (Identity)

Looking back now, what do you feel were the important barriers that stopped you from achieving what you wanted to?

Describe any links with your past ‘life’ when things were not going so well. (Knife off, any links with previous social networks, treatment etc).

What if anything could interfere with the success you have achieved now?

What strategies or tools or support do you use now to help maintain the success you have achieved?

What is the best thing about where you are now?

What are the difficult things about where you are now?

Reflecting on the positive changes you have made; how do you feel about yourself now?

### **Future treatment services**

Reflecting on your previous treatment experience and if money was not a barrier, describe your perfect treatment service.

### **Improving health and wellbeing**

(Reflect what the participant said doing well in treatment means for them)

In your opinion, what do you think could be done differently in treatment services to help or empower people (especially those who are on long term scripts) to get the best out of treatment?

I would like you to think about someone you know who has done really well in treatment. What was it about the treatment that helped them to do well? (Probes on other factors that helped them to do well too).

What would the perfect treatment service look like if money was not a barrier and you had complete control in designing the treatment service? (Prompts about staff, illicit use of heroin on script, support with health needs, offending and accommodation).

### **Closure**

Thank you and reflection of main points of interview.

Is there anything else you would like to add?

Is there anything that could have been done differently?

Debrief of purpose of interview and how findings will be disseminated.

Information on appropriate services for support if needed.

## **Appendix 3 - Schedule for online interviews with staff members**

### **Introduction and consent**

Brief description of project and aims

Consent form-anonymity and boundaries of confidentiality

Permission to record interview

Opportunity to ask questions what will be involved, and that participant can stop interview at any time

How are you today?

### **Demographic and work history**

Male/Female/Age/Education/Qualifications

Please tell me about how many years you have worked in the substance misuse field. (Probe contexts, duration of previous employment)

Thinking back to when you first started working in the substance misuse field, what motivated you to start working in the field of substance misuse field? (Elicit both external factors and internal factors- i.e care, professional development, qualifications, opportunity etc.)

### **Current role**

Tell me about the process of what happens when a person refers themselves to the service for difficulties with heroin use firstly a) pre COVID-19 and b) post COVID-19 (waiting list, COVID -19 situation, allocation of staff to clients and discuss the allocation criteria)

Please describe a typical working day pre and post COVID- 19 and how this impacts on OST clients achieving benefits from treatment (Role, elicit information on working practices, paperwork, time for breaks, relationships with staff/clients/management, how does this affect OST clients achieving benefits from treatment?).

The people who come to treatment for heroin all have different needs. How equipped do you think (name of Drug agency) is to meet these varying needs firstly a) pre COVID -19 b) and secondly post COVID- 19 (Please explain reasons)

When you receive a referral for heroin use, what are the key factors that make you think this client will not or do well in treatment and why? (Probe on gut instinct)

How did your thoughts/feelings affect your subsequent relation with this client and his/her benefits from treatment?

### **Treatment success/benefiting from treatment**

Thinking about a client who has been in OST how would you define success or ‘benefitting from treatment’? (Probe perceived connections with time frame and success)

How would other staff members/management/clients/commissioners define ‘benefitting from treatment’? (Elicit how it impacts on therapeutic relationship with clients and achievement of benefits from treatment)

When you receive a referral for heroin, what are the factors that will show a client will benefit from OST a) quickly b) slowly c) not at all?

### **What do you feel are the ingredients for success in OST?**

Please tell me if clients progress in treatment is currently monitored against the performance of staff members. (If no, what are your views on monitoring and what should be done with the data? Probe for views on the influence of staff members on achievement of benefits from treatment).

Tell me about a time when you or a colleague did something conventional or ‘unconventional’ that contributed to the client doing really well in treatment or engaging in treatment (i.e. Probe response or reaction to situation, medication, intervention)

Thinking back to when you first started doing the job, how much did you care that clients did well in treatment on scale of 0-10? (Elicit reasons why)

Nowadays, how much do you care that clients do well in treatment on a scale of 0-10 (Compare differences in numbers and elicit reasons why)

What impact has the current situation with Covid-19 had on OST patients? (Elicit positives and negatives)

Have you heard of Buvidal? (If not explain briefly) What are your thoughts on Buvidal? What impact will this have on OST patients benefitting from treatment?

### **Not currently benefitting from treatment**

How would you describe someone who is ‘not currently benefitting from OST’?

How would other staff members/management/clients/commissioners define ‘not currently benefitting from treatment’? (Elicit how it impacts on therapeutic relationship with clients and achievement of benefits from treatment)

How well do you feel that you know the barriers faced by clients in OST on a day to day basis?

Describe the most challenging time when you struggled with an OST client.

What do you believe were the main barriers in stopping them achieving their goals? (Elicit treatment related barriers and non-treatment related barriers and also extra barriers for females)

Thinking about a staff member or client who thinks completely differently from you, what would they say the barriers are?

### **Ways of improving health and wellbeing**

What do you feel is working well in treatment?

How do you think you could build on this further?

Imagine you woke up one day and it was the 'perfect day' in work, you felt that you could work to the best of your ability and OST clients were achieving the best out of treatment? What would that day look like pre-COVID -19 and post COVID -19?

Think about a long -term OST client who previously was struggling but is now doing really well in treatment. What helped them to do well? (Elicit key turning points)

If you could design the perfect dream treatment service for OST clients and you had no rules, treatment constraints what would the service look like? Just say the first ideas that come to your mind without worrying about practical, financial constraints etc.

### **Closure**

Anything else you would like to add?

Any ways in which interview could be improved?

Debrief

Thank you for your participation and time

## Appendix 4 - OST patient consent form

### Participant Consent Form

**Improving the health and wellbeing of people who are not benefiting from long-term opioid substitute treatment.**

#### Research Team:

Sharmila Mahesh Kumar (PhD student)

**Supervisory team:** Professor Katy Holloway, Professor Ali Wardak, Dr. Marian Buhociu and Sian Chicken

We are asking if you would like to take part in a research project to find out a) the reasons why some people are struggling to achieve benefits from long term OST and b) ways of improving their health and wellbeing. Before completing this form, you should have had the opportunity to read the participant information sheet and to ask the research team any questions you might have. If you have any questions before signing the consent form please speak to Sharmila.

**Please initial each statement to show that you agree with each statement and then sign the consent form to show that you agree with all statements.**

No.	Statement	Initials
1.	I have read and understood the participant information sheet ( <i>Version 1.1; Date: 23.10.20</i> ).	
2.	I have had the opportunity to ask any questions about the research being conducted.	
3.	I understand that my participation is voluntary and that I do not have to answer all the questions. I understand that I can stop the interview any time either temporarily or permanently.	
4.	I understand that my answers will be digitally recorded.	
5.	I understand that I will be asked questions about my experience in long term OST.	
6.	I understand that my data will be stored securely throughout the study under password protection on a secure University server. The data will be transcribed by a professional and confidential transcribing agency. Upon transcription, all identifiable data will be destroyed.	
7.	I understand that the information I give will be written up in a report and presented to other professionals. I understand this may be published. All names and identifying details will be anonymised.	
8.	I understand that the researcher will discuss data with their supervisors as needed.	
9.	I understand that disclosure of any illegal or unprofessional activity or anything that indicates harm to someone will be passed onto the appropriate authorities.	
10.	I consent to taking part in the study.	

**Signature**

**Counter signature**

**Date**

## Appendix 5 - Staff consent form

### Participant Consent Form

**Improving the health and wellbeing of people who are not benefiting from long-term opioid substitute treatment.**

#### Research Team:

Sharmila Mahesh Kumar (PhD student)

**Supervisory team:** Professor Katy Holloway, Professor Ali Wardak, Dr. Marian Buhociu and Sian Chicken

We are asking if you would like to take part in a research project to find out a) the reasons why some people are struggling to achieve benefits from long term OST and b) ways of improving their health and wellbeing. Before completing this form, you should have had the opportunity to read the participant information sheet and to ask the research team any questions you might have. If you have any questions or queries before signing the consent form please speak to Sharmila.

**Please initial each statement to show that you agree with each statement and then sign the consent form to show that you agree with all statements.**

No.	Statement	Initials
1.	I have read and understood the participant information sheet.	
2.	I have had the opportunity to ask any questions about the research being conducted.	
3.	I understand that my participation is voluntary and that I do not have to answer all the questions. I understand that I can stop the interview any time either temporarily or permanently.	
4.	I understand that my answers will be digitally recorded.	
5.	I understand that I will be asked questions about my experience in working with the OST population.	
6.	I understand that my data will be stored securely throughout the study under password protection on a secure University server. The data will be transcribed by a professional and confidential transcribing agency. Upon transcription, all data will be destroyed.	
7.	I understand that the information I give will be written up in a report and presented to other professionals. I understand this may be published. All names and identifying details will be anonymised.	
8.	I understand that the researcher will discuss data with their supervisors as needed.	
9.	I understand that confidentiality may need to be broken if there is a perceived risk to myself or others. In these circumstances, I will be informed of the reasons why confidentiality may need to be broken.	
10.	I consent to taking part in the study.	

## Appendix 6 - Information sheet for OST patients

### Participant information

**Improving the health and wellbeing of people who are not benefiting from long-term opioid substitute treatment.**

#### **Time to change gear in long term Opiate Substitution Treatment (OST)?**

My name is Sharmila and I am conducting this research at University of South Wales, Treforest in partnership with (name of Drug agency).



#### **What is the study about?**

When heroin is used on a regular basis, the user may experience flu like withdrawal symptoms when he/she suddenly stops using heroin. Methadone and buprenorphine are opiates which are prescribed by doctors and nurses at treatment agencies. This treatment is called Opiate Substitute Treatment (OST). OST has been shown to be effective in improving the wellbeing of people who use heroin. However, there is still a number of people who are still using heroin despite being engaged with treatment services for five years or more. This study aims to find out a) why people are still using heroin despite being engaged with treatment services for five years or more and b) find effective ways of improving the health and wellbeing of this long-term OST population. The results will help us to understand more about the barriers faced by the long-term OST population. It is hoped that the results will help to inform the development of interventions that could improve the health and wellbeing of the long-term OST population who are currently not benefiting from treatment.

#### **Why have I been approached?**

You have been approached because you are using heroin and have been with treatment services for five years or more. You may have been approached because you are a staff member or volunteer who has direct experience in working with people who are still using heroin and have been with OST for five years or more. You may also have been approached if you had previously used heroin and had a history of OST for five years or more.

Information is needed from the above three groups to help answer the research questions of a)

what barriers are faced by people who are still using heroin and in treatment services for five years or more and b) ways in which the health and wellbeing can be improved for this OST group.

**Do I have to take part?**

No. It's completely up to you to decide whether or not you take part.

**What will I be asked to do if I take part?**

As a participant you will be interviewed for up to an hour in a venue at the drug agency. The interviews will be digitally recorded. The questions will explore what you feel are the barriers in stopping people achieving benefits from treatment. You will also be asked your view on what could be done differently to help improve the health and wellbeing of OST patients who are still using heroin and working with treatment services for five years or more. I understand that confidentiality may need to be broken if there is a perceived risk to myself or others. In these circumstances, you will be informed of the reasons why confidentiality may need to be broken. You will be debriefed once you have completed the study.

**Will my data be identifiable?**

No, interview data will be anonymised. Data will be stored securely throughout the study under password protection on a secure University server. The data will be transcribed by a professional and confidential transcribing company that has been used by the Director of Studies. Upon transcription, all data in which you could be identified will be destroyed. You will be presented with a consent form with a list of statements that you will be required to sign.

**What happens to the results?**

The results from this project will be written and submitted as part of my thesis for my PhD qualification in Social Policy and Criminology by University of South Wales. Your results will also be included in reports to both (name of Drug agency) and Her Majesty's Prison and Probation Service (HMPPS). The results may also be published in journal articles. Participants will also be debriefed about the results at a debrief meeting.

## Appendix 7 - Information sheet for staff members

### Participant information

#### Improving the health and wellbeing of people who are not benefiting from long-term opioid substitute treatment.

My name is Sharmila and I am conducting this research at University of South Wales, Treforest in partnership with (name of substance misuse agency).



#### What is the study about?

When heroin is used on a regular basis, the user may experience flu like withdrawal symptoms when he/she suddenly stops using heroin. Methadone and buprenorphine are opiates which are prescribed by doctors and nurses at treatment agencies. This treatment is called Opiate Substitute Treatment (OST). OST has been shown to be effective in improving the wellbeing of people who use heroin. However, there is still a number of people who are still using heroin despite being engaged with treatment services for five years or more. This study aims to find out a) why people are still using heroin despite being engaged with treatment services for five years or more and b) find effective ways of improving the health and wellbeing of this long-term OST population. The results will help us to understand more about the barriers faced by the long-term OST population. It is hoped that the results will help to inform the development of interventions that could improve the health and wellbeing of the long-term OST population who are currently not benefiting from treatment.

#### Why have I been approached?

You may have been approached because you are a staff member or volunteer who has direct experience in working with people who are still using heroin and have been with OST for five years or more. You may have been approached because you are using heroin and have been with treatment services for five years or more. You may also have been approached if you had previously used heroin and had a history of OST for five years or more. Information is needed from the above three groups to help answer the research questions of a) what

barriers are faced by people who are still using heroin and in treatment services for five years or more and b) ways in which the health and wellbeing can be improved for this OST group.

**Do I have to take part?**

No. It's completely up to you to decide whether or not you take part.

**What will I be asked to do if I take part?**

The interview slots will be pre-arranged at a time that is convenient for you, but this can be changed at any time should that prove necessary. As a participant you will be interviewed online for up to an hour via google meet. The interviews will be digitally recorded. The questions will explore what you feel are the barriers in stopping people achieving benefits from treatment. You will also be asked you view on what could be done differently to help improve the health and wellbeing of OST patients who are still using heroin and working with treatment services for five years or more. I appreciate that you have agreed to participate in the interview in these unprecedented circumstances of working from home. You can stop the interview at any time if required by circumstances or you do not wish to answer any more questions. Confidentiality may need to be broken if there is a perceived risk to yourself or others. In these circumstances, you will be informed of the reasons why confidentiality may need to be broken. You will be debriefed once you have completed the study.

**Will my data be identifiable?**

No, interview data will be anonymised. Data will be stored securely throughout the study under password protection on a secure University server. The data will be transcribed by a professional and confidential transcribing company that has been used by the Director of Studies. Upon transcription, all data will be destroyed. You will be presented with a consent form with a list of statements that you will be required to sign.

**What happens to the results?**

The results from this project will be written and submitted as part of my thesis for my PhD qualification in Social Policy and Criminology by University of South Wales. Your results will also be included in reports to both (name of substance misuse agency) and HMPPS. The results may also be published in journal articles. Participants will also be debriefed about the results at a debrief meeting.

### **Are there any benefits to taking part?**

There are no direct benefits, but you may find it helpful to talk about your experiences and it is a chance for your view to be heard. Furthermore, improved long term health and social wellbeing of the OST population could enhance job satisfaction, motivation, increase morale which in turn could strengthen benefits to the long-term OST population.

### **Who has reviewed the project?**

This project has been approved by the HMPPS, and by the USW Faculty of Business and Society Research Ethics Committee.

### **Where can I obtain further information about the study if I need it?**

If you have any questions or require further information you can contact me via email on [sharmila.maheshkumar@southwales.ac.uk](mailto:sharmila.maheshkumar@southwales.ac.uk).

Complaints: If you wish to raise a concern or make a complaint regarding this project and you do not want to report this to the research team, please contact: Jonathan Sinfield, USW Research Governance Officers at the University of South Wales ([jonathan.sinfield@southwales.ac.uk](mailto:jonathan.sinfield@southwales.ac.uk), 01443 484518).

### **Resources in the event of distress**

Should you feel distressed either because of taking part, or in the future, the following information may be helpful. Samaritans operate a 24-hour confidential telephone support service and can be contacted for free on Tel: 116 123 (UK).

Should you feel upset because of taking part, you can also speak to your line manager or participate in online group supervision sessions. The line manager and the facilitator of the supervision sessions will be able to support you or help you in accessing relevant services.

If you feel that you need further support, you should speak with your GP or local mental health team for information about support in your local area.

Thank you for taking the time to read this information.



## **Appendix 8 - Application for ethical approval to conduct online interviews with staff members during the COVID-19 pandemic**

### **Ethical considerations for online interviewing of staff members**

*Improving the health and wellbeing of the long-term opiate substitute treatment population who are currently not benefiting from treatment*

#### **Introduction**

Corona virus is a virus that can be seen in animals and humans (Department of Health and Social Care (DHSC, 2020). COVID-19 is a new virus that has not previously affected humans and is believed to have originated in Wuhan, China (DHSC, 2020). On 30 January 2020, the World Health Organisation announced that this virus was of international concern. The absence of immunity to this virus and vaccine increased the risk of spreading the virus in the UK (DHSC, 2020). Symptoms of the corona virus may include a persistent cough, an increased temperature and/or shortness of breath (DHSC, 2020). The Corona Virus Bill 2020 allowed for the introduction of social distancing measures as a means of containing the virus (DHSC, 2020). The UK Government issued guidance that social contact should be avoided unless necessary. In response to this guidance, the criminology department at the University suspended all face to face interviews in March 2020.

The purpose of this report is to present ethical considerations of conducting online interviews with staff members at a substance misuse agency in South Wales. This report aims to give brief description of the Project, overview of ethical issues that had been submitted to the University of South Wales in 2018 and describe the current progress of the thesis. The report also aims to a) identify potential ethical issues associated with conducting online interviews with staff members and b) explain how these ethical concerns will be addressed.

#### **Brief description of Project**

My interest to apply for this proposal was initiated by my experience of working with long-term opiate substitute treatment (OST) patients who were struggling to improve their health and social wellbeing, especially in light of the recent treatment model of the substance misuse agency to move from substitute medication towards detoxification. Given my background in working with vulnerable long-term OST clients, my passion to develop innovative interventions to empower them to improve their wellbeing will be reflected in my research practice.

Research has shown that OST is highly beneficial in improving the health and social wellbeing of heroin users. However, there is a significant proportion of heroin users on long term OST who are struggling to achieve benefits from treatment, which raises the question of what could be done to improve these individuals' wellbeing as well. The research will involve interviewing three groups of participants: a) people who have a history of five years or more of being engaged with long term OST but are struggling to improve their wellbeing b) people who have a history of five years or more of being engaged with long term OST and who were previously struggling to improve their wellbeing, but have now experienced

significant improvements in their wellbeing and c) staff members who have direct experience of working with the previously mentioned populations.

### **Overview of ethical issues raised by face-to-face interviews with staff members (previously submitted to University of South Wales for ethical approval in August 2018)**

The fair mnemonic states that people must be treated fairly, autonomy must be respected, the researcher must act with integrity and must seek the best results possible by avoiding or minimizing harm and by using resources as beneficially as possible (University of South Wales General Ethical Guidelines for Research and Consultancy, 2016). This fair mnemonic was used to explain how the ethical challenges posed by this study will be overcome to protect participants from potential harm and achieve the best findings possible. The participants will be fully informed of circumstances in which confidentiality will be broken prior to participation in research in accordance with the substance misuse agency's confidentiality policy i.e. risk of harm to self, risk of harm to another and risk to children. Staff members will also be informed that confidentiality will be broken if disclosures affect the welfare of clients and conflicts with current confidentiality policies of the substance misuse agency. In accordance with British Society of Criminology (2015) ethical guidelines, participants will also be informed that confidentiality will be broken if there is a suspected act of terrorism and money laundering. Similarly, in circumstances of disclosure of malpractice or inappropriate behaviour by another member of staff, confidentiality may need to be broken if the disclosure affects the welfare of service users and conflicts with current policies of the substance misuse agency.

Anonymity is important to ensure the maintenance of confidentiality and to ensure that the identity of participants is protected. The identity of staff members could be identified by management through responses given at the interview. As a potential solution, staff will be reassured prior to interviews that their responses are intended to improve health and social outcomes. Quotations will be anonymized in reports/chapters to protect the identity of participants. All anonymised data will be stored securely on University servers and upon transcription all data will be destroyed. Data will be transcribed by Avonlea (a professional and secure transcribing agency that is used by the DoS). Fully informed consent will be gained i.e. it will be freely given, based on information that is appropriate to the participant's level of understanding and not influenced by deception. Participants will be clearly informed that the purpose of the research is to improve social and health wellbeing for those long term OST patients who are struggling to achieve their goals, as possibly their specific needs are not being met by current services. Research could indirectly improve staff morale as it gives them an opportunity for their perspectives to be heard. Participants will be signposted to appropriate services such as Women's Aid, The Samaritans, Citizens Advice Bureau etc.

### **Current progress of the PhD thesis**

From December 2019 to March 2020, I was in the process of interviewing long term clients who perceive themselves 'not to be currently benefitting'(NCBT) from opiate substitute treatment (OST). During this period, I was also interviewing participants who had previously perceived themselves to be not benefitting from treatment, but now saw themselves as succeeding in treatment (formerly NCBT population). In light of Governmental advice and

guidance from the criminology department at the University of South Wales, face to face interviews were suspended in light of the Corona Virus pandemic in March 2020. I therefore stopped face to face interviews in response to guidance from the University of South Wales in March 2020.

In April 2020, I discussed the possibility of conducting online interviews with my supervision team and the Director of the substance misuse agency has given consent for staff members to be interviewed. It was decided that it would be inappropriate to conduct online interviews with clients of substance misuse agencies because of confidentiality and ethical issues. My Director of Studies discussed the possibility of staff interviews with Professor Howard Williamson. It was agreed that I should submit a document stating how I will address ethical issues associated with online interviews of staff members.

### **Additional ethical issues associated with conducting online interviews with staff members**

#### *Current situation with corona virus pandemic*

The NHS (2020) advised that people should stay at home unless they are:

- shopping for basic necessities, for example food and medicine, which must be as infrequent as possible
- one form of exercise a day, for example a run, walk, or cycle – alone or with members of your household
- any medical need, including to donate blood, avoid or escape risk of injury or harm, or to provide care or to help a vulnerable person
- travelling for work purposes, but only where you cannot work from home

The current situation therefore is that most staff members of the substance misuse agency will be working from home. A limited number of staff will be delivering medication to clients who are self-isolating and/or will be involved in the delivery of needle exchange services.

#### *Informed consent and arrangement of interviews*

An email will be sent to staff members detailing the project, what will be involved, and potential participants will also be given the opportunity to ask questions prior to participation via email or telephone. Participants will be informed that their participation is voluntary, and they can withdraw from the study at any time. It is anticipated that the online interviews with staff members will be conducted via Skype at a pre-arranged time slot that is convenient for the participant. Consent forms will be emailed to participants and electronically signed forms will be returned by email. Participants will also be emailed a debrief form following completion of the online interview. The data will be transcribed by Avonlea (a professional and confidential transcribing company). Upon transcription, the audio recorded data will be destroyed.

#### *Balancing work with childcare commitments*

As schools are currently closed due to the corona virus pandemic, staff members who are parents will be involved in either home schooling their children or looking after their pre-school children. Interviewees will be therefore faced with the additional demand of balancing

childcare with work commitments. To help resolve this issue, interview slots will be pre-arranged at a time that is convenient for the participant, although participants will be informed that this can be changed at any time should that prove necessary. Participants will also be informed that they can stop the interview at any time including because of childcare commitments.

#### *Potential anxiety of participants*

Participants may be anxious that their responses may be identifiable by management and their responses could affect their employment. Participants will be informed that the purpose of the project is to improve the wellbeing of OST patients and responses will be anonymised. Participation will also be voluntary and there is no obligation to participate. It is anticipated that some participants will be anxious about their jobs and incomes in this currently uncertain economic climate. It is likely that some participants may express anxiety about how their employment may be affected by the current situation with the corona virus pandemic. It is also expected some participants will be anxious about potential risk to themselves, family members, friends, clients etc. Participants may also be socially isolated because of the current lockdown stipulations. Reflective listening skills will be used by myself to convey empathy. Participants will also be given the opportunity to speak to their line manager, access online group supervision sessions offered by the substance misuse agency, Samaritans helpline, Women's Aid etc. The balance between maximising time resources and safety to participants/researcher will be achieved through interviewing staff members via Skype. This will ensure that social distancing is maintained but data is also collected.

#### *Confidentiality*

There may be risks to confidentiality given that staff members will be using their computers at home. However, staff members at the substance misuse agency have been issued with GDPR guidance on using their computers safely at home i.e. Staff have been instructed to use encrypted computers and lock their screen when not in use (Kaleidoscope, 2020). Staff have also been instructed to ensure that their computer screens are not visible from windows or by other people who may enter the room (Kaleidoscope, 2020). Given that staff are already accustomed to working from home and staff members have been issued with GDPR guidance, it is anticipated that most participants will already mitigate any risks to confidentiality i.e. using a suitable workplace etc. I will also confirm with participants that they are situated in a venue that is comfortable and confidential for them. Another potential risk to breaches of confidentiality is if names of other staff members or names of clients are mentioned during the interviews. In these circumstances, all names will be anonymised unless the disclosure breaches confidentiality policies.

#### *Potential benefits to staff members*

In face to face interviews, rapport prior to the interviews was normally established by offering tea/ biscuits etc, to help the participant feel comfortable. In these unprecedented circumstances, icebreaker questions will be used to help the participant feel comfortable i.e. How are you feeling today? The participant will also be put at ease by giving the opportunity to ask questions of what will be involved and that they will only need to answer the questions that they wish to answer. Participants will also be given the opportunity to withdraw from the interview at any time. Participants will be thanked for their participation and time. They will also be asked if they feel there is any way in which they feel that the interview could be improved. It is anticipated that this question will help improve the interview experience for future participants. It is expected that the research will benefit other staff members too i.e., staff members will have an opportunity for their voice to be heard. Furthermore, improved

long term health and social wellbeing of the OST population could enhance job satisfaction, motivation, increase morale which in turn could strengthen benefits to the long-term OST population.

## **References**

Department of Health and Social Care (2020) *Corona virus action plan: a guide to what you can expect across the UK*. Available at:

<https://www.gov.uk/government/publications/coronavirus-action-plan/coronavirus-action-plan-a-guide-to-what-you-can-expect-across-the-uk> (Accessed: 30 April 2020).

Kaleidoscope (2020) *Home working data protection guidelines*.

NHS (2020) *Staying at home and away from other people (social distancing)* Available at:

<https://www.nhs.uk/conditions/coronavirus-covid-19/staying-at-home-to-avoid-getting-coronavirus/staying-at-home-and-away-from-other-people/> (Accessed: 30 April 2020).

Appendix 9 - Sample of thank you card given to all participants

