
PERSON-CENTRED CANCER CARE FOR WALES

Viewpoints from Professionals, Managers and Stakeholders

for Macmillan Cancer Support, Wales

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ACKNOWLEDGEMENTS AND SCOPE OF REPORT

This Report is based on a series of telephone and face to face interviews and an online questionnaire conducted with professionals, managers and stakeholders working in cancer services in Wales 2010. It adds to existing evidence collected by Macmillan – on the views of service users and their families, and the policy context in Wales – and needs to be read in this context.

Macmillan staff – and in particular Cath Lindley, Susan Morris and Gwenllian Griffiths – have been instrumental in shaping the study. The project Steering Group provided important insights at the design stage of the study, and has been a helpful influence in ensuring the report is as relevant as possible. We should also kindly acknowledge the contributions of respondents – either via interview or questionnaire – for without them the study would not have been possible.

The issues identified contained herein are based solely on the evidence presented to us by the respondents. Whilst we have attempted to be true to what was said, the interpretation of responses offered here are entirely our own and any errors are due to the authors.

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EXECUTIVE SUMMARY

1. Person centred care is defined as high quality care that treats people with sensitivity and compassion and regards them as a person and not just a patient. Such care needs to be holistic in its planning and delivery and extends beyond clinical care to address wider social, financial, emotional, practical, psychological and spiritual concerns.
2. The professionals in cancer care clearly want to provide more person-centred care. They recognise the importance of this issue, and the shortcomings of many aspects of current provision, and their views accord with those of patients and carers as expressed in Macmillan's other research.
3. Although standards of clinical care – especially in the treatment phase - are generally very good and improving, most aspects of current provision could not be described as 'world class' in terms of their 'person centredness'. The deficiencies are most obvious in relation to
 - a. Living with and after cancer – including post-treatment assessment and care planning, empowering patients to help themselves, and access to non-clinical support and information
 - b. Early diagnosis
 - c. Choice of place of death
4. Several 'cross-cutting' aspects of provision also require attention, including:
 - a. the role and function of 'key workers'
 - b. the provision of more integrated and coordinated care
 - c. the impact of geography on access to services
 - d. out-of-hours provision, and
 - e. the needs of carers and families.
5. The ability to translate good intentions into practice appears to be frustrated by a lack of a clear national strategic approach to cancer in Wales. Professionals would wish to see such an approach adopted, combined with local application to meet the differing needs of the various communities across Wales.

1 INTRODUCTION, CONTEXT AND METHODOLOGY

INTRODUCTION

This report has been prepared to assist Macmillan Cancer Support in defining their vision for person-centred cancer services in Wales for the next five years. It draws upon findings from a research project commissioned by Macmillan that was carried out by the Welsh Institute of Health and Social Care, University of Glamorgan (WIHSC) between June and October 2010.

Macmillan Cancer Support in Wales is committed to the development and delivery of efficient and effective person centred services for all people affected by cancer in Wales. Their goal is to ensure that people receive high quality care that treats them with sensitivity and compassion and regards them as a person and not just a patient. Such care needs to be holistic in its planning and delivery and extends beyond clinical care to address wider social, financial, emotional, practical, psychological and spiritual concerns.

Macmillan has carried out a number of listening exercises throughout Wales with service users and carers affected by cancer. Although generally happy with the clinical care they receive, Macmillan found that many people affected by cancer were not getting adequate support to address their full needs. This study complements those views with the insights of people involved in providing cancer services in Wales, focusing in particular on what might be done to support change.

CONTEXT FOR THE STUDY

This study forms part of a programme of work that Macmillan Cancer Support has undertaken to support the development of a more person-centred approach to cancer in Wales.

This work has involved a number of strands. In 2009 Macmillan commissioned research to assess the position of cancer policy in Wales. The resulting report, authored by Professor Siobhan McClelland, 'Does Wales Need a Cancer Strategy?' identifies the strengths and weaknesses of current and past approaches to planning cancer services in Wales so as to inform future direction.¹ Following on from that, this year Macmillan commissioned a YouGov poll in Wales to demonstrate the extent to which the general public thinks that cancer, and specifically cancer support, should be a priority for the Welsh assembly Government (WAG).²

The most important dimension of the work has been to gather evidence from people living with cancer. People who live with cancer are a powerful resource whose knowledge and experience of cancer services are invaluable in helping to bring about change. Macmillan has carried out a number of surveys and workshops with patients and carers throughout Wales to identify where the gaps lie in existing support services and to explore how these might be addressed. In general, people were happy with the standard of clinical care but many people were not receiving the emotional, practical and financial support and information they needed.³

¹ 'Does Wales Need a Cancer Strategy?' Macmillan 2009

² CPPA Summer 2010 UK Cancer patient survey. Macmillan 2010

³ 'Having your Say' Report. Macmillan 2008

Macmillan Cancer Support wants to see all people affected by cancer receive the support and information they need. Their goal is to ensure that people receive high quality care that treats them with sensitivity and compassion and regards them as a person and not just a patient. Such care needs to be holistic in its planning and delivery and extends beyond clinical care to address wider social, financial, emotional, practical, psychological and spiritual concerns.

Many of the components of person-centred services have been demonstrated as leading to improved outcomes such as more efficient disease management, reduction in unnecessary resource utilisation and reduced costs.⁴

Although cancer is the second most common cause of death in Wales more and more people are surviving longer after a cancer diagnosis. The number of people living with or after cancer in Wales will double over the next twenty years to over 200,000 people, representing 7% of the population.⁵ This poses significant challenges to the NHS, social services and the voluntary sector. With the survival rate from cancer improving, there is a need to focus beyond the acute, clinical phase to the management of cancer and the effects of cancer treatment as a chronic condition encompassing a range of services.

The National Standards for Rehabilitation of Adult Cancer Patients were published in April 2010.⁶ Although cancer rehabilitation is a recent concept in the United Kingdom, evidence suggests that the early identification of rehabilitation needs can improve quality of life, maximise independence and through self management reduce the NHS burden.

Cancer rehabilitation has been defined by the Wales Nursing and Allied Health Professional Cancer Advisory Group as:

“The process that assists a person with cancer to obtain maximum physical, social, psychological and vocational functioning from the time of diagnosis, treatment planning, and during and after treatment. Rehabilitation in cancer can be preventative, restorative, supportive and palliative. It is recognised that patients may have rehabilitation needs throughout their care pathway, and that these needs should be assessed at key points on the pathway.”⁷

Taking a person-centred approach means understanding the patient with cancer in a wider context. However the recent vision statement from the National Cancer Survivorship Initiative warns that the shift from traditional, clinically-led models of acute care to a more holistic planning process will involve dramatic cultural and attitudinal change.⁸ There needs to be a common commitment to the values of person centred care although it is argued that for many practitioners this appears to be a widely used but poorly understood concept. Work by the King’s Fund highlights the ambiguity that exists in defining ‘patient centred care’ between policy makers and care practitioners, and states that “the challenges in delivering and improving patient-centred care include finding a shared

⁴ Demonstrating the Economic Value of Co-ordinated Cancer Services: an examination of resource utilisation in Manchester by the Monitor Group, Macmillan 2010

⁵ <http://wales.gov.uk/topics/statistics/headlines/pop2009/hdw20091021/>

⁶ The National Standards for Rehabilitation of Adult Cancer Patients, Welsh Assembly Government, April 2010

⁷ Wales Nursing and Allied Health Professional Cancer Advisory Group (NAHPCAG) 2008)

⁸ National Cancer Survivorship Initiative Vision Statement. Department of Health, Macmillan Cancer Support and NHS Improvement, January 2010

language for health professionals and managers to discuss it”.⁹ Hence the importance of this piece of research work which aims to better understand the views of the cancer workforce and those who plan cancer services in Wales about person centred care and the barriers that they perceive in making the aforementioned shift.

METHODOLOGY

Key Questions:

- In the view of professionals, managers and stakeholders working within cancer services in Wales, how do current policies and practices support the delivery of person-centred services for people living with and after cancer?
- What are the key challenges to delivering person-centred care and how can they be overcome?

Our starting point for this study was to try and discover what exactly do professionals involved in providing cancer services in Wales understand by the term person-centred care. For the purposes of this study person-centred cancer care was defined as:

High quality care that treats people with sensitivity and compassion. Such care is holistic in its planning and delivery and extends beyond clinical care to address wider social, financial, emotional, practical, psychological and spiritual concerns.

Our intention was to engage with a range of stakeholders across Wales; across different types of cancer; across clinical and non clinical services; and across all sectors of the NHS, voluntary and other statutory sectors. We wanted to explore how much, in theory and in practice, their interpretation differed from Macmillan’s vision. Leading on from this we wanted to find out more about the challenges involved in providing person-centred services; where and how do current policies and practices relating to cancer support the delivery of such services; and where there is a need for change.

A mixture of data collection methods was used to engage the views of a broad section of stakeholders and health professionals working within cancer care services in Wales. This was predominately a qualitative investigation allowing participants to respond more extensively and in greater detail than is typically the case with quantitative methods. Through the use of open-ended questions and a flexible interview schedule participants had the opportunity to respond in their own words, rather than being forced to choose from fixed responses. The intention was to develop a richer understanding of how services work, their constraints and opportunities, by listening to those providing them.

An initial round of face to face interviews with a number of carefully selected key stakeholders was followed by telephone interviews with prominent cancer leads. People were asked to comment on four key areas of interest:

- What exactly is understood by the term ‘person-centred cancer care’?
- How much person-centred care is currently being delivered?

⁹ http://www.kingsfund.org.uk/topics/patientcentred_care

- How can cancer services become more person-centred?
- To what extent do person-centred services need to be cancer specific?

We then invited the views of a wider group of people involved in providing cancer care throughout Wales. As well as NHS staff such as Consultants, GPs, Nurses, Allied Health Professionals and Managers, this included professionals working within the local authority and the third sector. Around half of our potential participants were drawn from Macmillan professionals; other sources included the Cancer Services Coordinating Group and the Cancer Networks, Royal College of Nursing, Royal College of General Practitioners and a number of organisations within social care and the third sector.

Potential participants were asked to complete an online open-text survey. The survey was developed by WIHSC in conjunction with Macmillan Cancer Support, Wales and members of the project steering group. It was based upon the evidence supplied by service users, their families and carers to Macmillan about the care they receive. It was divided into two parts. The first part consisted of four sections with each section corresponding to a different stage of the cancer journey:

1. Diagnosis and Decision Making
2. Treatment
3. Living With and After Cancer
4. End of Life Care

In the second part, respondents were asked to give their views on whether current Welsh policy promotes the delivery of person centred cancer care.

Whilst the response rate to this survey was limited we were heartened by the depth and details of the responses we received and feel confident that, together with the interview data, we have managed to capture the views of a significant number of well respected and well informed practitioners, managers and others from across Wales.

2 RESEARCH FINDINGS

In total we received the views of 77 people involved in providing cancer services in Wales: 21 who agreed to be interviewed, and 56 who offered detailed responses via an online open-text survey. A detailed description of the on-line survey is contained in Appendix 1 (Design of Questionnaire). We received responses from a broad range of professionals throughout all of Wales with all specialities and tumour sites represented. (See Appendix 2: Characteristics of questionnaire respondents and Appendix 3: Questionnaire results). The information that they provided is presented in two parts:

1. Are cancer services person centred?

Respondents to the online questionnaire were presented with a series of statements written from the perspective of someone who was in the post treatment phase. They were asked to indicate how often, based upon their knowledge and experience, someone who had been treated for cancer would be able to agree with each statement. We wanted to get a sense of whether the situation was improving and so we asked people to consider services as they are provided currently ('Now') and as they were two years ago ('2 years ago'). In our findings we have displayed a traffic light alongside each element. This traffic light is coloured **green, amber** or **red**. A red traffic light shows that less than 40% of the respondents thought that people regularly receive this type of care and that this element of person centred care needs urgent attention. An amber traffic light shows that between 40 and 69% of respondents thought that people frequently receive this type of care but there are some significant shortcomings to address. A green traffic light shows that 70% or more of the respondents thought that most people received this type of care most of the time. Although it is encouraging to see a number of areas awarded a green light, it is important to proceed with caution as there are still aspects of care in these areas that need to be improved. These aspects are highlighted below the green lights.

2. How can the delivery of person centred services be improved?

Through the use of the open text questions and during the interviews participants were encouraged to explore why services are being delivered as they are and what could be done to make services more person centred. A number of common concerns emerged relating to key stages in the cancer journey and cancer policy in general. To illustrate these concerns we have reproduced comments from a range of respondents.

2.1 DIAGNOSIS AND DECISION MAKING

KEY POINTS

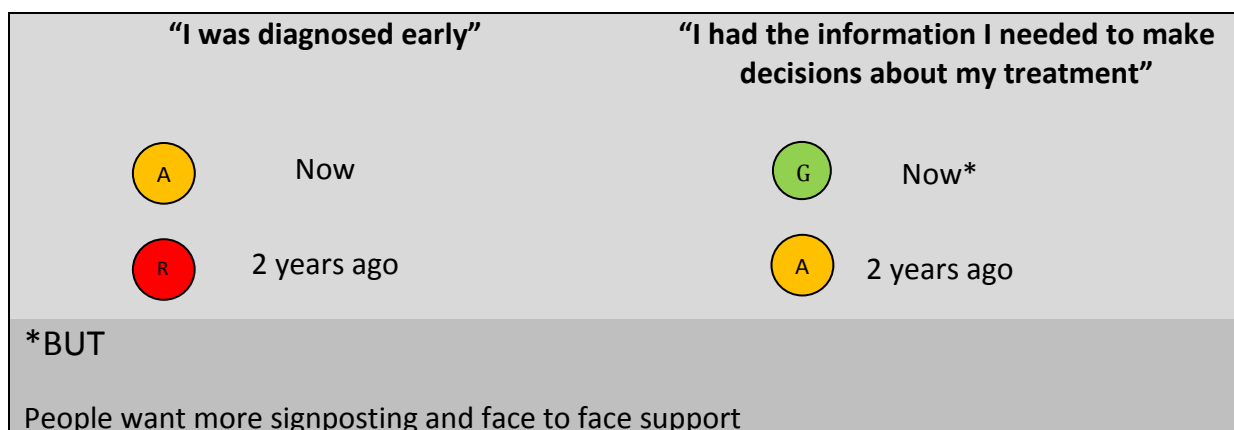
Diagnosis and Decision Making:

- Early detection and diagnosis is improving but patients and GPs are sometimes slow to act upon symptoms
- Poorly coordinated referral processes and complex diagnostic pathways can cause unnecessary delays
- The quality of information available has greatly improved but people need help to navigate their way through it
- People should have access to somebody that they can talk to about a range of clinical and non-clinical needs at all stages of their cancer treatment and aftercare

Overall Strengths and Weaknesses and Direction of Travel

Respondents were asked:

According to your knowledge and experience, how often do you think people who have been treated for cancer would be able to agree with the following statements:



Detailed Findings

For a number of cancers, the survival rates for patients in Wales are poorer than many other countries in Europe. There is evidence that cancer is being detected and diagnosed later in Wales and that this is a significant factor in the poor survival rates.¹⁰ Improving the detection of cancer was a key goal in *Designed to Tackle Cancer (2006)*¹¹ and a number of measures were introduced to address this including the time to treatment target for cases of Urgent Suspected Cancer (USC). Amongst our respondents there was general agreement that more people are being diagnosed earlier and that the reasons for late diagnosis broadly fell within two categories: late presentation and diagnostic delays. There were a number of factors implicated in late presentation. It was felt that patients were sometimes slow to recognise or respond appropriately to the signs and symptoms of cancer. However, once referred, most patients appeared to progress relatively swiftly

¹⁰ Eurocare 4. Lancet Oncology 8:8 August 2007

¹¹ *Designed to Tackle Cancer in Wales: a Welsh Assembly Government Policy Statement*, December 2006

along the diagnostic pathway. The exceptions to this included patients where diagnosis and staging was a more complex process. Although this often related to the nature of their disease, for example some of the rarer cancers or where the primary cancer was of unknown origin, it was reported that patients who needed to be referred out of area often experienced unnecessary delays due to poor communication and liaison between services.

“I believe that patients do not always seek help in a timely way and as a consequence can present late. I think that there are 2 reasons for this either not understanding the significance of symptoms or hoping that it isn't serious and will go away. Although this isn't so much the case in the commoner cancers (due to media and certain charities) in the rarer cancers this can be the case” [Operational Manager, Survey]

“Unfortunately many GP's are not recognising the early symptoms and is a major contributor to late diagnosis. Especially so with certain cancers where a patient may make several visits to their GP, before further tests are initiated. For example we have had several cases where our clients have visited the doctor on several occasions presenting with symptoms of low back pain, to be diagnosed with 'muscle strain, lumber pain etc, when subsequent investigations result in a diagnosis of prostate cancer. However once diagnosed and into the specialist/hospital environment, patients are in our experience treated quickly and given detailed information about the various treatment pathways available to them” [Doctor, Survey]

“Whether a patient is diagnosed early depends on the individual going to the GP at a stage when they know something is wrong or hoping that the problem will go away. I have known many patients who admitted they should have sought help earlier, yet it also depends on the awareness of the GP when the patient does go to the GP and the time constraints the GP is under” [Nurse, Survey]

“Sometimes the delay is not because there has been a failure in the system it's because purely and simply they need to get an appropriate diagnosis and in order to do that sometimes they need to do more tests. Sometimes you have a patient and everyone knows that patient had cancer but the tests are not actually proving conclusive so that's when reporting on waiting times falls down” [Nurse, interview]

On a positive note there was a general consensus that the introduction of referral time to treatment targets had improved waiting times, although several respondents sounded a note of caution about this:

“The staging process is now more streamline with clinicians deciding on a plan early in the staging process and explaining possible investigations that may be needed, so following MDT discussion the CNS is able to phone with next stage cutting out the need for coming back to clinic to explain the next step. The relationship with medical team and patient is far more flexible not as rigid” [Nurse, Survey]

“I personally think patients are diagnosed earlier now compared to 2 years ago, however I think the patients and their families might think differently. From a secondary care perspective the referral time to treatment targets have reduced a patients time to treatment, which as a result has also reduced time to diagnosis. However where patients are not identified by their GP's as Urgent Suspected cancer and graded as such at the hospital, their

diagnostic pathway will not have been managed to the same strict timeframes” [Doctor, Survey]

Our attention was drawn too to the fact that it is not simply about how long a patient has to wait but how they are supported during that wait:

“You can’t get rid of the wait but a patient needs to feel they have been listened to and have had a clear explanation of the process and the doctor has reassured them that the wait won’t be detrimental to their condition. That is patient centred care” [Doctor, Interview]

Information and support at diagnosis

Information and support are central to helping people affected by cancer to negotiate their way through their cancer journey. Although reference to the provision of information and support is contained in a number of Welsh Assembly Government policy statements there is no overarching national strategy ensuring the appropriate design or delivery of such services.¹²

The National Cancer Standards state that written information, in an appropriate language and format, should be offered to each new cancer patient. It should cover general information about specific treatment options, the multi-disciplinary team and support services. Many of our respondents felt that although this type of information was increasingly available, patients often found it overwhelming, especially when first diagnosed. They wanted to see more attention focused on the process of information giving with patients having time to absorb what they were being told and the opportunity to ask questions outside of the consulting room.

“The situation has improved with information but perhaps we’ve gone from one extreme to another – fact sheets everywhere. We must take the cue from the patient about what they want and when” [Strategic Manager, Interview]

“Often patients are bombarded with paper and verbal information but they need someone to talk through it and help them understand what it means for them as a person” [Doctor, Interview]

“Information needs can vary according to the cancer diagnosed, this can still be very fragmented and needs a very flexible approach to the individual needs of the patient and carer” [Information Worker, survey]

Receiving the right information is a vital component in empowering patients to have the confidence and competence to make decisions about their treatment and needs to be given in ways that are meaningful:

“Whilst information is available it is not always given in ways that inform. Medics usually try to explain treatment options etc in terms of percentages, figures from trials, quoting 5 years survival rates which can cause distress as patients only hear 5 years. They focus on this, feeling that they have been given a prognosis. Often they are sent away with no checking of understanding and are expected to make a decision with this information and no psychological support to do so. I guess what I am trying to say is that information is there, often in copious amounts, but it is not person centred” [Nurse, Survey]

¹² Designed to Tackle Cancer Strategic Framework (2008-11); Designed to Improve Health and the Management of Chronic Conditions in Wales 2007; Primary & Community Services Strategic Delivery Programme 2009; Rural Health Plan 2009

“Patient leaflets and booklets have improved, but I think more could be done locally with better access to specialist nurses to provide additional support and a point of contact for a patient and/or their family to ask questions outside of formal consultation with a doctor/consultant” [Operational Manager, Survey]

2.2 TREATMENT

KEY POINTS

Treatment:





- Once diagnosed most people begin treatment promptly
- Most people are satisfied that the treatment they receive is the best available for their cancer, and for their life. They understand that this may not be available locally and are pragmatic about the inconvenience this involves
- The treatment phase still tends to have an overwhelmingly medical focus – people need help to identify and access support for their other needs
- Families and Carers should be given more information and support to meet their practical and emotional needs

Overall Strengths and Weaknesses and Direction of Travel

Respondents were asked:

According to your knowledge and experience, how often do you think people who have been treated for cancer would be able to agree with the following statements:

Once diagnosed my treatment and care started promptly	I received the care and treatment that were best for my cancer	I received the care and treatment that were best for my life
 Now*	 Now**	 Now ***
 2 years ago	 2 years ago	 2 years ago

I was treated with dignity and respect		Those around me were well supported	
	Now		Now
	2 years ago		2 years ago
<p>BUT – There are still concerns around:</p> <ul style="list-style-type: none"> * Delays in receiving treatment ** Access to treatment *** Care and support for the non-clinical needs of people affected by cancer and their families 			

Detailed Findings

It was widely felt that, once diagnosed, most people started their treatment promptly and that this treatment was perceived by patients as the best available for their cancer, and their life. There were exceptions and we were particularly concerned to hear of a number of operations for head and neck cancer being postponed due to a lack of intensive care and surgical beds. It was felt that most patients were treated with dignity and respect, a core element of person-centred care, during their treatment.

There was far less agreement though as to the extent that the treatment phase could be described as truly person centred. It was acknowledged that the major consideration for almost all patients at this stage was around the quality of the clinical care they received. Many of our respondents reported feedback from people affected by cancer that supported this. We were told too that generally patients accepted the financial and geographical limitations that prevented them from accessing treatment close to home. Patients, it was suggested, were fairly pragmatic about lengthy travel to specialist centres for treatments if they believed that these treatments constituted the best care available to them. However there was growing unrest about the inequity of access to specialist drugs and treatments compared to England.

“For a patient during the acute phase the priority is getting expert treatment regardless of what compromises or inconveniences that involves in other areas such as travel. Patients are far less critical of shortfalls in the system than staff are. It’s very frustrating for me to have to contend with unnecessary delays. I think the capacity to deliver treatment in a timely fashion should be a minimum expectation” [Doctor, Interview]

“Overall we are treating patients as quickly as we can within the constraints of the NHS and with the best treatment we have available. Where we have issues are with what is best for life - that is difficult to define but we know in some cases treatment might actually not draw much benefit and arguably might not be best for quality of life as oppose to quantity of life. I still think we have difficulty providing support for carers and this is not seen as core NHS business - it should be” [Doctor, Survey]

“The provision of high cost chemotherapy treatments in particular and advanced radiotherapy techniques are often unavailable in Wales even though public knowledge about them is much

more advanced. Therefore this is beginning to cause anxieties with some patients as to whether they have received all possible treatments” [Manager, Survey]

Very often cancer is a complex condition requiring the input of many different practitioners. This can be a bewildering experience for patients who are sometimes shunted between different departments and different hospitals with little explanation. Poor liaison and communication can also lead to unnecessary delays in treatments and tests:

“Individual professionals are kind, but the systems and processes are disjointed so it can be very confusing and reliant on a sole person to provide co-ordinated care and take overall responsibility” [Nurse, Survey]

Some professionals expressed their frustration that non-clinical needs were often poorly addressed during the treatment phase and spoke of the need to challenge the prevailing medical culture of “a system that often believes that as long as you get the medical and physical side of care right, that is adequate care” (AHP, Interview). A significant number of respondents highlighted the lack of support for families and carers during this phase:

“Support for carers is generally woeful and left almost entirely to the voluntary sector. Poor provision leads to a multiplicity of problems in regard to emotional support and the practicalities involved in supporting and caring for a person with cancer. The cancer treatments phase is quite rightly extremely focussed on the medical aspects of care. However, other aspects of holistic care (psychological, emotional, practical and spiritual) are often neglected. The situation cannot fully change unless we fully integrate all aspects of care into MDT meetings, which are still largely comprised of medical, surgical and oncological colleagues” [AHP, Survey]

There was a sense that the dominant focus is still very much a medical one, of treating the condition rather than the individual. However as many pointed out – to provide care that is genuinely person-centred would require a substantial increase in two resources that are always in short supply: time and money:

“Over the past two years there has been a significant rise in awareness of all issues surrounding cancer, not least, the emotional aspects of such a diagnosis. Individual staff in the health service are dedicated and have a depth and warmth which offers great support to the patient. It is the resources that Wales lack; the resources to act promptly in a timely manner, to fund enough specialist nursing staff & to fund other support staff who may offer guidance and support to a family member and/or carer of someone who has cancer” [AHP, Survey]

2.3 LIVING WITH AND AFTER CANCER

KEY POINTS

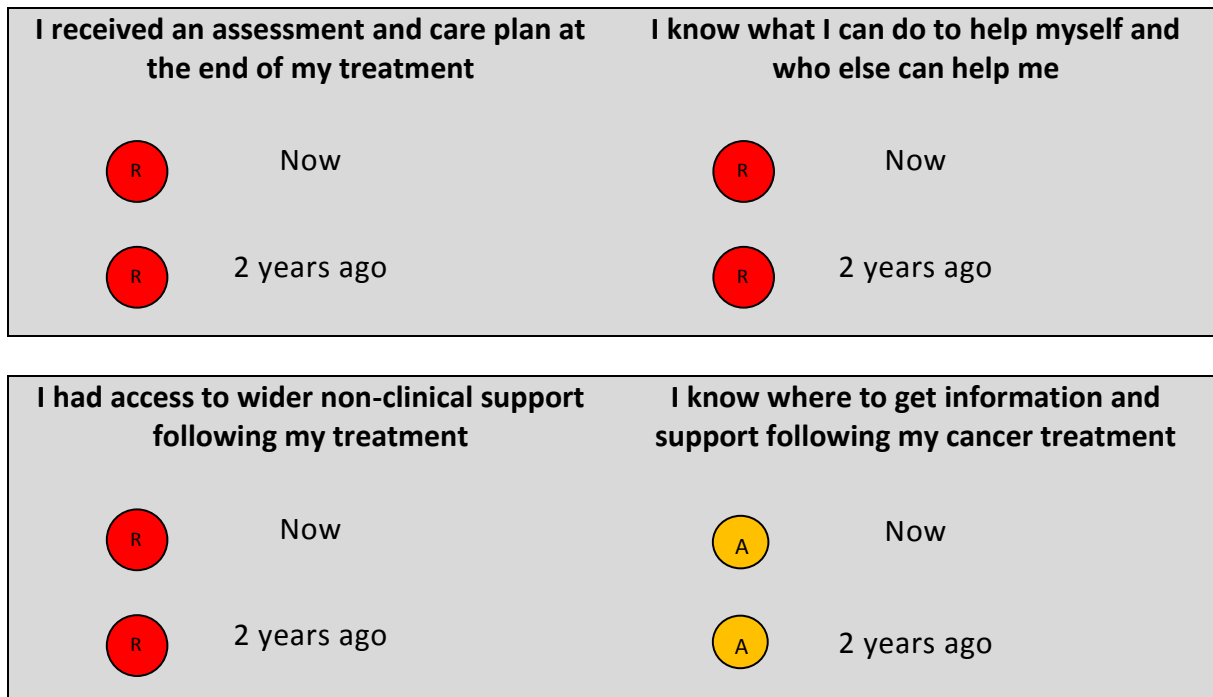
Living with and after cancer:

- People are often left adrift after treatment finishes. This can be a time when their support needs are particularly pressing.
- Appointing a Keyworker may be a good idea in principle but there has been too little thought given to how this initiative will be implemented in practice. There needs to be more clarity about how the role is defined and delivered.
- The Keyworker may need to change at different stages of the cancer pathway; how this transition is organised is important. The Key worker could be particularly important in providing support in the post treatment phase.
- People should be given the skills to self manage their care if possible but currently cancer rehabilitation is underfunded. Some aspects of rehabilitation could be delivered by a generic programme.
- The current system of routine follow up should be re-designed.

Overall Strengths and Weaknesses and Direction of Travel

Respondents were asked:

According to your knowledge and experience, how often do you think people who have been treated for cancer would be able to agree with the following statements:



Detailed Findings

As the 'traffic lights' show, this was the area where services experience most difficulties in providing person centred care, and where improvement seems to be slowest. A number of recurring issues were identified that can be loosely grouped into three overlapping themes:

- Follow up and self management
- Rehabilitation – specialist or generic?
- The Role of the Keyworker

Follow Up and Self Management

There is increasing evidence that the current system of routine face-to-face follow up is an expensive and, in many cases, ineffective way of detecting recurrence of cancer. A recent study by the Monitor Group for Macmillan in Manchester demonstrated the potential savings that could be achieved through the coordination of care. By providing a comprehensive discharge assessment, supported self care in the community and swift and simple access back into secondary services expenditure on cancer care was shown to be significantly reduced.¹³

For people whose lives had been affected by cancer, not only would such measures improve health outcomes, but much of the anxiety and confusion that many patients experience at the end of their treatment could be greatly alleviated. Several respondents mentioned the long shadow of fear that cancer casts over people's lives and the need for people to regain confidence in their own health. People need individually tailored information about what to look out for and who they can contact if they have concerns.

"Following treatment patients can feel isolated and uncertain where to seek help. During treatment phases they always have a contact point but following this, although they may be seen in arbitrary OPDs, who they should contact if they have concerns can be less clear"
[Doctor, Survey]

"I have not come across a patient or family member being given an assessment and care plan following treatment. Most will be given dates of treatment, letters re OPA's and verbal information. Sometimes leaflets re procedures. Some patients may not feel enabled or confident to initiate seeking information, don't want to be a burden and bother people, don't like making a fuss. Some may not want information, many pts like little information as frightened" [Nurse, Survey]

"There is still an overwhelming response of abandonment following treatment which has not improved. The promotion of living with cancer initiatives is extremely slow in availability. Obtaining NHS funding for these more supportive issues is difficult which has led to a reliance on charities" [Operational Manager, Survey]

"I am aware assessment and care planning is a key priority in England...Local audits have highlighted patients do not want to bother CNS as too busy and their query/concern is not that important. Open access is reiterated also review with GP/district nursing team" [Nurse, Interview]

¹³ Demonstrating the Economic Value of Co-ordinated Cancer Services: an examination of resource utilisation in Manchester by the Monitor Group, Macmillan 2010

“We need a more flexible follow up system! Currently (and this true of primary and secondary care) the follow up models are much more nursing and medically centred than patient centred” [Doctor, Survey]

“It must be possible to reorganise routine follow up so that, by a large number of patients, it is self managed /needs led. And make use of things like Telehealth!” [Strategic Manager, Interview]

Rehabilitation – specialist or generic?

People need help to develop the skills of self management. Some professionals wanted to see more resources directed towards patient education and rehabilitation but emphasised that these should be structured to be responsive to patient needs:

“From rehab point of view it has to be what that person wants at that point of time. Can’t impose it on someone and needs are very different, depending on what type of person they are, the treatment they’ve had, their support needs etc. It has to be as individual as possible” [AHP, Interview]

“Patients should after initial treatments be provided with written information: risk of cancer returning for them, signs to look out for, informed of why a healthy lifestyle is beneficial (reduce risk of recurrence for one), importance of returning to previous social activities. Perhaps a specialist nurse along with other allied health professionals could run survivorship (or called something similar) classes on a rolling programme to address all these issues. Actually some could be imparted to patients at different time scales during their treatment-at the teachable moment” [Nurse, survey]

Existing rehabilitation programmes, such as those used in cardiac care, provide a useful model and it was felt that serious consideration should be given to delivering rehabilitation as a generic rather than cancer specific service.

“In principle people could go on the cardiac rehab programme but there is no funding. There are lots of elements that can be generic but the big barrier is funding as that is specific” [AHP, Interview]

“I think there could be more ‘skilling up’ of generic services. Like welfare and benefits advice – that pertains to other chronic conditions” [Strategic manager, Interview]

“Rehabilitation has become an important issue for people living with cancer in Wales (finally!). However, with no financial support for the rehabilitation agenda, and with services focusing very much on the physical aspects of rehabilitation, rather than actually living with the full range of difficulties encountered by people who have cancer, such services are likely to fall well short of a holistic service that enables people to live a full life with (or beyond) cancer. Without financial backing and staff who will provide the full range of highly specialist support to patients living with cancer, the government's rehabilitation standard will be delivered in a tick box fashion, which will potentially create further reliance on traditional hospital services” [Operational Manager, Survey]

The Role of the Keyworker

The question of specificity is central to the discussions around the role of the Keyworker. In line with the requirements of the Standards for the Rehabilitation of Adults with Cancer published in April 2010, Local Health Boards have been advised that each patient diagnosed with cancer must have a nominated Keyworker to coordinate their care for the duration of their treatment in secondary care and subsequently within primary care via their GP. It is stated that these Keyworkers will need to link closely with the local integrated Chronic Conditions Management Teams. Each LHB is expected have in place a Keyworker for each cancer patient, by the end of March 2011.

From our responses it would appear that there are significant concerns around the implementation of the Keyworker initiative. It was universally felt that there needed to be ‘considerably more thinking through’ and a better attempt to define the role. Without this, the lack of consensus as to who and what a Keyworker should be would inevitably lead to inconsistencies in and between services:

“It’s ‘playing politics’, I think the Keyworker has been chosen as the easiest and quickest of the rehab standards to implement but no one has thought about what it actually means” [Strategic Manager, Interview]

“If you are going to say that every patient is told they have a Keyworker and then you are going to describe something that sounds like – what’s the expression – motherhood and apple pie? I don’t think GPs are going to feel that they are going to be able to take that role on. And a couple of things that are said about the Keyworker, you wonder what it is that this person is going to be doing. You see a description that says things like the Keyworker will be able to rapidly get the patient back to clinic. Well, I think that’s an interesting one!” [Doctor, Interview]

That said, the principle of providing every patient with a named person responsible for coordinating their care and support needs was well received, however the complexity of the cancer pathway makes it difficult to identify who is best placed to carry out this role.

Some professionals remarked that the role being described simply mirrored that of a good GP. Most suggested that in practice a patient would have a number of different Keyworkers along their cancer journey and that it would be vitally important to ensure a smooth and coordinated handover between each:

“It will be an incredibly complex process to implement. Logically it needs to be a different person at each stage e.g. the CNS in hospital, the AHP for rehab etc” [Strategic Manager, Interview]

“You could argue the practice nurse and district nurse are the Keyworkers. They are the people who see patients on a regular basis. Then if you go into the secondary setting it would be the CNS but then there would be no flow and that’s where you need to make sure it doesn’t fall down. The CNS needs to know that the patient is handed over to someone when they go back into primary care and vice versa” [Nurse, Interview]

“Clearly it needs to be specialist when going through active treatment. Probably doesn’t need to be cancer specific when its palliative care – it needs to be palliative care specific. I think the

bit in the middle is the thing that hasn't really been addressed in the past and think there is an argument to address it specifically – and generically" [Doctor, Interview]

The question as to whether, following the active treatment phase, a Keyworker could be generic rather than a cancer specialist was one that many people were undecided about. Many felt that the most important stage for a Keyworker to be appointed was once treatment had finished with a particular emphasis on helping to meet 'non clinical' needs. For many patients the practical, financial and, indeed, emotional impact of their cancer diagnosis only fully hits them after the phase of active treatment is over but it was suggested by several respondents that patients are left feeling 'high and dry' at a time when they may need the most support:

"Patients and relatives have to source their own support at a time when they are floundering. It appears that once the disease has progressed to the palliative and end of life stage support is copious. Those who need rehabilitation and psychological support to live with their disease or former disease do not get it" [AHP, Survey].

It appears that few people receive any sort of formal plan of care at the end of their treatment. Again, this was identified as a key function of the Keyworker, who would need to possess both the practical knowledge and authority to help a patient access the support they need:

"You need someone who is able to signpost people. They need to know what is available but they have to be able to draw down services if need be" [Operational Manager, Interview].

Having an overview of available support was something that many professionals acknowledged was done considerably better by the third sector than the NHS. There was much praise for third sector provision particularly in terms of providing practical and emotional support:

"Charities are better placed in some respects to deliver this type of support. They do not carry the same 'medical associations' that many people are keen to avoid and are often more creative in the support they provide. They also provide opportunities to give something back which a lot of people with cancer really want to do" [Operational Manager, Interview]

"Although there are many support groups qualified to provide counselling and complementary therapies for clients and their carers the information is not always passed onto the clients at the hospital or GP surgery" [Operational Manager, Survey]

"There are excellent voluntary agencies which provide broad reaching services for people with cancer. However, new rehab services developing locally have identified a large group of people who may never have received support in developing the skills required for living after cancer. Some people continue to tell us that they haven't heard of the supports available, or feel they would not meet eligibility. They benefit greatly once told that they are and encouraged to self refer to these organisations" [AHP, Survey]

"The survivorship approach is in its infancy and to a large degree patients living with cancer are still left to their own devices. I don't believe much has changed. A key issue is definition, there are different points of view. In addition the NHS does not see this as core business and as a result the approach is fragmented. Best support is probably the internet. It would be great if the NHS could see it as core business" [Operational Manager, Survey]

2.4 END OF LIFE CARE

KEY POINTS

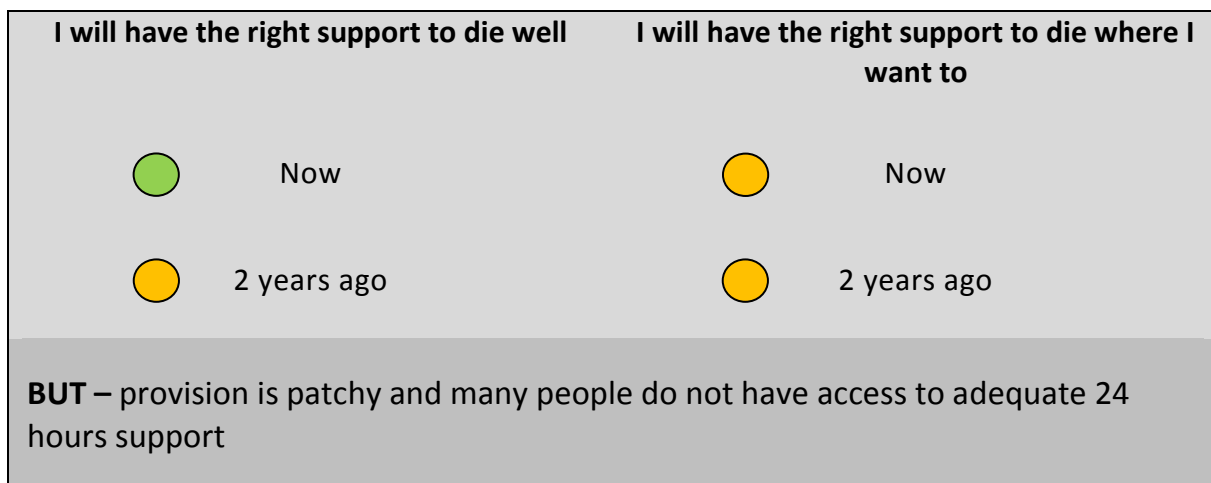
End of life:

- There has been substantial progress in delivering palliative care in many areas but still provision throughout Wales is patchy
- Out of hours care needs improving
- Deciding where to die is a complex issue but insufficient resources can limit patient choices

Overall Strengths and Weaknesses and Direction of Travel

Respondents were asked:

According to your knowledge and experience, how often do you think people who have been treated for cancer would be able to agree with the following statements:



Detailed Findings

Care for people with cancer at the end of life was thought to be the most person centred part of the cancer journey and there was praise for the work done by the Palliative Care Strategy Implementation Board led by Baroness Finlay, and the previous work led by Viv Sugar¹⁴. The Dying Well Initiative was attributed with helping to bring about big improvements in the last few years. However there was concern that the provision of palliative care was still patchy with significant variations between the LHBs.

“A lot of work has been done on 'dying well' in recent years. Expertise is available and more widespread. Symptom control and nursing support of the dying is better, but I am not confident whether patients and their carers unilaterally feel they can decide where the best

¹⁴ The Sugar Report on palliative care provision in Wales (June 2008): <http://wales.gov.uk/topics/health/publications/health/reports/palliativecare/?lang=en>

place is to die and a lot depends on the availability of dedicated nurses meeting the patient in their own home” [AHP, Survey]

“Facilities for end of life care are poor. Those involved do the best they can, but with NO hospice beds in the trust and inadequate and inexperienced carers in the community the choices are limited and medicalised. I suspect the requirements of the All-Wales end of life strategy are not able to be fulfilled and there is little commitment to achieve this” [Nurse, Survey]

Out of hours care appeared to be particularly problematic:

“Some clients have the support they require and this is of great help to their family after their loved ones had died. But pressure on the system, insufficient palliative care resources, and financial support to allow patients to die at home for example, means that we receive feedback to indicate that the support network isn't there for many terminally ill patients. We hear horrendous stories from anguished carers who are not able to get a nurse at night for example. In other cases their loved ones having to wait in severe pain before a doctor or nurse is available to administer the necessary medication” [Nurse, Survey]

“I believe that the provision of out of hours services in terms of general palliative care remains patchy in certain areas. Specialist palliative care has undoubtedly improved with 7/7 CNS and 24/7 telephone advice but whether this is always accessed in a timely and appropriate way... Also access to out of hours equipment i.e. commodes, beds, slide sheets (things that can make the difference between admitting someone who wants to stay at home and keeping someone at home in the event of a sudden change in someone’s condition) is poor in many areas” [Doctor, Survey]

“The processes to improve facilitation of death at home have not improved. The complex and lengthy continuing healthcare forms and funding does delay the patient. The availability of equipment to support a patient and family dying at home is poor and professionals have become risk adverse in issues such as provision of hospital beds. The implementation of GSF in primary care will help improve this area but the provision of out of hours primary care services does not support this ethos” [Manager, Survey]

2.5 POLICY

KEY POINTS

Policy:

- Many people would like to see a new, more detailed and wider reaching cancer strategy for Wales
- Need for Clinical Leadership and an overhaul of the way services are monitored and reviewed
- There is a lack of consistency in resource allocation and standards of care across Wales
- Need for better coordination between services with joint care pathways developed between health services, local authority and voluntary sector.

The National Cancer Standards define the core aspects of the service that should be provided for adult cancer patients throughout Wales. As well as using them in conjunction with

recommendations and guidelines from other bodies such as NICE, the Health & Safety Executive and the Royal Colleges, Local Health Boards are encouraged to work to more rigorous and wide ranging standards and provide additional services as appropriate.

We asked people whether they were aware of national and local policies that supported the delivery of person centred cancer services and whether they believed these policies were well implemented. We also asked them what they would like to see done about policy in Wales to ensure better implementation of person centred cancer care in their area.

Most people knew of the national policy initiatives but there was a general perception that the implementation of these was patchy and poorly planned. Several people drew comparisons between the Home Nations, bemoaning the fact that *Designed to Tackle Cancer* is not as detailed or far reaching as the cancer strategies in place in England or Scotland. Although people thought the Standards had initially been a useful way of driving through change in some areas e.g. with subspecialisation and the development of multi-disciplinary teams, the annual monitoring process was described as bureaucratic, inflexible and cumbersome. Many of the measures do not accurately reflect the real state of cancer services and it was suggested that it was time for an overhaul of service evaluation with several people advocating a move towards peer review and accreditation. There was also concern about the lack of clinical leadership with some respondents supporting the introduction of a National Cancer Director in Wales to drive through change.

“I am very aware of cancer policies. However, often the implementation is poorly planned and results in haphazard execution. There is a risk that patient-centred care will fall prey to a tick-box approach to ensure that it is achieved on paper” [AHP, Survey]

“National policy is very person-centred but there appears no dynamics about bringing this to reality. Everyone has to buy into the need for this at a day to day level and be supported in initiatives to implement it. Most NHS workers think they do patient centred care already and at the patient level do – but they need to recognise where organisational priorities skew the delivery to patients and strive to reduce them. Managers need to appreciate where organisational barriers have a negative impact on service delivery” [Doctor, Survey]

“We need a robust peer review system that focuses on clinical indicators alongside PROMS. It could run in parallel” [Strategic Manager, Interview]

It was recognised that many of the issues are not unique to cancer services. In particular, the challenges presented by the rural geography of Wales and the need to strike a balance between meeting local needs and having a population of sufficient size to plan and implement the efficient use of scarce resources.

“It’s difficult in Wales to accrue a large enough population. If you look at the site specific cancers and what NICE says about how they should be managed and what the population is that they should be delivered to, then sometimes in Wales it difficult to achieve that population without delivering in clusters” [Interview, Strategic Manager]

Even so people felt that the variations in service provision between LHBs were often unacceptable and there needed to be more robust population based planning. It was felt that some of the inequalities in access could be addressed by better integration and coordination between the NHS, Social Services and the Third Sector with organisations encouraged to work together.

“Geography and the policies of LHBs sometimes impact negatively on person-centred provision of care e.g. people living near a boundary on one side of an LHB may live closer to a cancer centre in the next LHB than they do to the one in the area in which they live. This means they have to travel a round trip of 45- 50 miles instead of 20 to access their care” [Nurse, Survey]

“I’d like to see joint training and exploration of how joint care pathways can work realistically at operational level, not just rhetoric. Using the expertise learned from the managing chronic conditions programme would be beneficial” [Strategic Manager, Survey]

“We need more truly caring front line staff who are well trained and signed up to working together for the greater good of the patient and their family. This includes home care support & professionals able to respond quickly and efficiently and REAL joint working between Health and Social Services which includes housing and voluntary sector to provide a true holistic approach to Person-centred cancer care. Teams based together and MDT working help address professional issues and strengthen communication and speed up processes in my opinion” [AHP, survey]

3 CONCLUSIONS

The health professionals, managers and other stakeholders in this study were asked to give their view on how well person centred care is currently being delivered in Wales, and whether provision was improving. They were asked to comment on the key elements of person centred care that every patient should expect to receive at different stages of the cancer pathway.

Although standards of clinical care – especially in the treatment phase of the patient pathway - are generally very good and improving, most aspects of current provision could not be described as ‘world class’ in terms of their ‘person centredness’. The professionals in cancer care clearly want to provide more person-centred care. They recognise the importance of this issue, and the shortcomings of many aspects of current provision, and their views accord with those of patients and carers as expressed in Macmillan’s other research. The ability to translate good intentions into practice appears to be frustrated by a lack of a clear national strategic approach to cancer in Wales. In the view of professionals, managers and stakeholders in this report, such an approach should be adopted, combined with local application to meet the differing needs of the various communities across Wales.

Key Themes

Overall, the following key themes emerge from this report:

DIAGNOSIS AND DECISION MAKING

1. Early detection and diagnosis is improving but patients are sometimes slow to act upon symptoms
2. Poorly coordinated referral processes and complex diagnostic pathways can cause unnecessary delays
3. The quality of information available has greatly improved but people need help to navigate their way through it
4. People should have access to somebody that they can talk to about a range of clinical and non-clinical needs at all stages of their cancer treatment and aftercare

TREATMENT

1. Once diagnosed most people begin treatment promptly
2. Most people are satisfied that the treatment they receive is the best available for their cancer. They understand that this may not be available locally and are pragmatic about the inconvenience this involves
3. The treatment phase still tends to have a overwhelming medical focus – people need help to identify and access support for their other needs
4. Families and Carers should be given more information and support

LIVING WITH AND AFTER CANCER

1. People often left adrift after treatment finishes. This can be a time when their support needs are particularly pressing
2. Appointing a Key Worker is a good idea in principle but there has been too little thought given to how this initiative will be implemented in practice. There needs to be more clarity about how the role is defined and delivered.

3. The Key Worker may need to change at different stages of the cancer pathway; how this transition is organised is important. The Key Worker could be particularly important in providing support in the post treatment phase.
4. People should be given the skills to self manage their care if possible. Currently cancer rehabilitation is underfunded. Some aspects of rehabilitation could be delivered by a generic programme.
5. The current system of routine follow up could be improved.

END OF LIFE

1. There has been substantial progress in delivering palliative care in many areas but still provision throughout Wales is still patchy
2. Out of hours care needs improving

POLICY

1. Many people would like to see a new, more detailed and wider ranging cancer strategy for Wales
2. Need for Clinical Leadership and an overhaul of the way services are monitored and reviewed
3. There is a lack of consistency in resource allocation and standards of care across Wales
4. Need for better coordination between services with joint care pathways developed between health services, local authority and voluntary sector

Of these, three areas were identified as particularly deficient:

- **Living with and after cancer**

The improvement in cancer survival rates together with an ageing population means that the number of people living with and beyond cancer in Wales is rapidly increasing. It is imperative that services turn their attention towards helping these people to resume everyday activities and to live as healthy and active a life as possible for as long as possible. Professionals in this study recognised the need to provide post-treatment assessment and care planning but reported that this rarely happens. They were aware of the many practical and emotional difficulties faced by people in the post-treatment stage and felt that patients and carers would benefit from better signposting towards sources of information and non-clinical support.

Although important at all stages of the cancer pathway, the role of the Key Worker was most frequently mentioned in the post-treatment context. Professionals echoed the views of their patients in that they felt the role had great potential to provide coordinated, needs-led care and support. However there were many reservations about the implementation of the Key Worker initiative in Wales so far, and concerns that too little strategic planning and evaluation would result in an ill-defined role and patchy delivery.

Many professionals advocated a shift from the traditional clinically-led system of follow-up to a supported self-management approach. In addition to the comprehensive assessment and care planning process mentioned earlier, this would require a programme of patient education and rehabilitation and a service designed to respond to individual patient needs, coordinated across primary, secondary and third sector health and social care services.

- **Early Diagnosis**

There is evidence that cancer is being detected and diagnosed later in Wales and that this is a significant factor in survival rates which, for a number of cancers, are poorer than many other countries in Europe. Our respondents reported that measures such as the referral time to treatment targets had improved this situation. However there are still a number of reasons why cancers are not being diagnosed earlier.. Patients and GP were felt to be sometimes slow to act upon symptoms. Poorly coordinated referral systems between primary and secondary services and complex diagnostic pathways can also lead to unacceptable delays.

- **Choice of place of death**

Professionals welcomed the work that has been carried out in Wales around End of Life care and acknowledged that significant improvements had been made in this area as a result. However access to out of hours care was a significant concern raised by many respondents as was the impact of geography upon access to palliative care at home. As a result it was felt that many people are not able to exercise real choice regarding the place of care during their final days.

Cross-cutting themes

In addition, several 'cross-cutting' themes were repeated across most areas of person-centred cancer care. These included:

- geographical inequalities - people living in the more isolated communities often enjoyed less provision than those in the urban centres. This is an issue which the Health Boards will need to address as they work through the implications of the rural health plan;
- the role and function of 'key workers' – greater clarity and agreement is still required on certain of the defining characteristics of this role;
- the provision of more integrated and coordinated care – patients do not always experienced an easy and assured transfer between elements of service provision, especially at the interface between the NHS and other providers;
- out-of-hours provision – patients in some parts of Wales cannot be assured of first class support when the main centres of provision are not operating; and
- the needs of carers and families – service providers are often focused entirely on the needs of the patient, and the ability of the carer and family to support the patient is sometimes taken for granted.

These issues need to be addressed at each stage of the cancer journey.

APPENDIX 1 | Design of Questionnaire

The online survey was developed by WIHSC in conjunction with Macmillan Cancer Support, Wales and members of the project steering group. It was based upon the evidence supplied by service users, their families and carers to Macmillan about the care they receive. It was divided into two parts. The first part consisted of four sections. Each section corresponded to a different stage of the cancer journey:

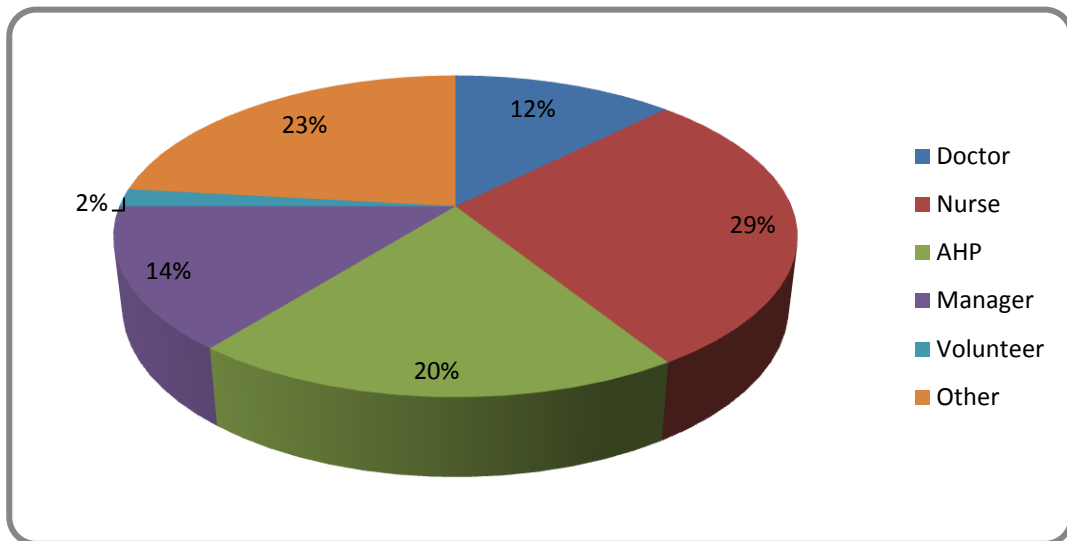
1. Diagnosis and Decision Making
2. Treatment
3. Living With and After Cancer
4. End of Life Care

Within each section people were presented with a number of statements that related to key elements of person-centred care at that stage of the pathway. They were asked to assess how often patients received these key elements and to comment on the factors affecting this (a) currently and (b) two years ago. They were then asked to identify the biggest challenges to delivering person centred cancer care for services in Wales and what could be done to address this. In the second part, respondents were asked to give their views on whether current welsh policy promotes the delivery of person centred cancer care.

In order to encourage a full and frank response from as many people as possible, the survey was designed to be answered anonymously. Participants were not asked to disclose any information from which they could be identified such as job title or place of work but they were asked to provide some broad demographic details. People were asked to indicate which category they considered their post to fall within (Medical, Nursing, Managerial, AHP, Volunteer or other; whether they worked within the NHS, Statutory or Third Sector; whether they were based mainly in community or hospital services and whether they worked primarily with cancer patients. Those people working mostly with cancer patients were also asked to indicate which type(s) of cancer they primarily dealt with.

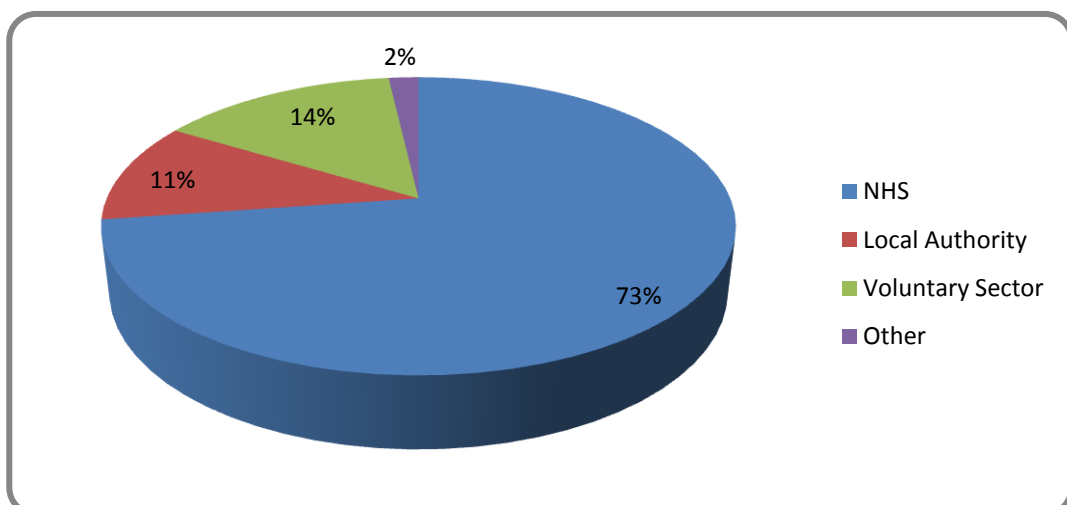
APPENDIX 2 | Characteristics of Questionnaire Respondents

Figure 1 | Which of the following best defines your role?



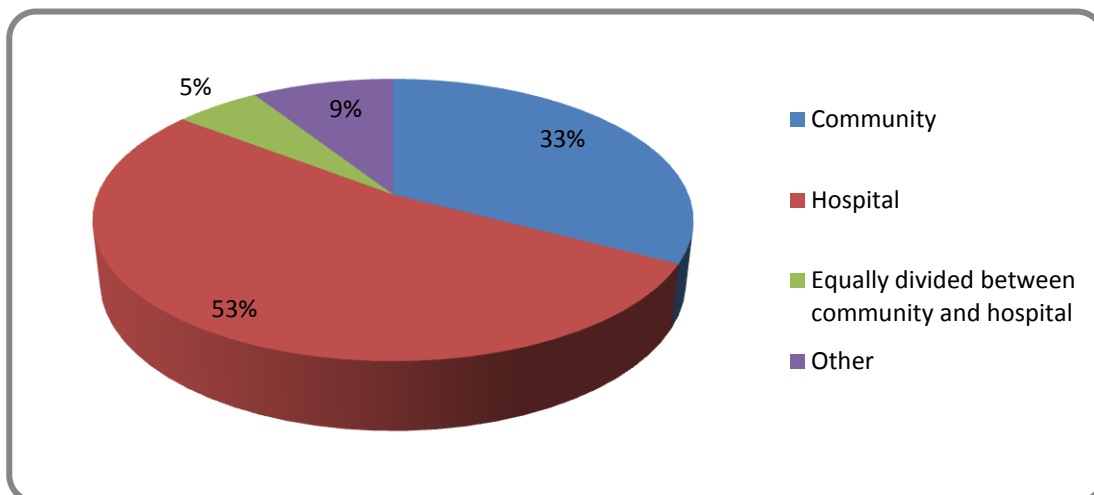
Doctor	7	12.7%
Nurse	16	29.1%
AHP	11	20.0%
Manager	8	14.5%
Volunteer	1	1.8%
Other <i>Carer support worker x2; Social Worker; Information Coordinator x 2; Policy Officer x2; Benefits Advisor; Patient Involvement Facilitator x2</i>	13	23.6%

Figure 2 | Which organisation/ sector do you work within?



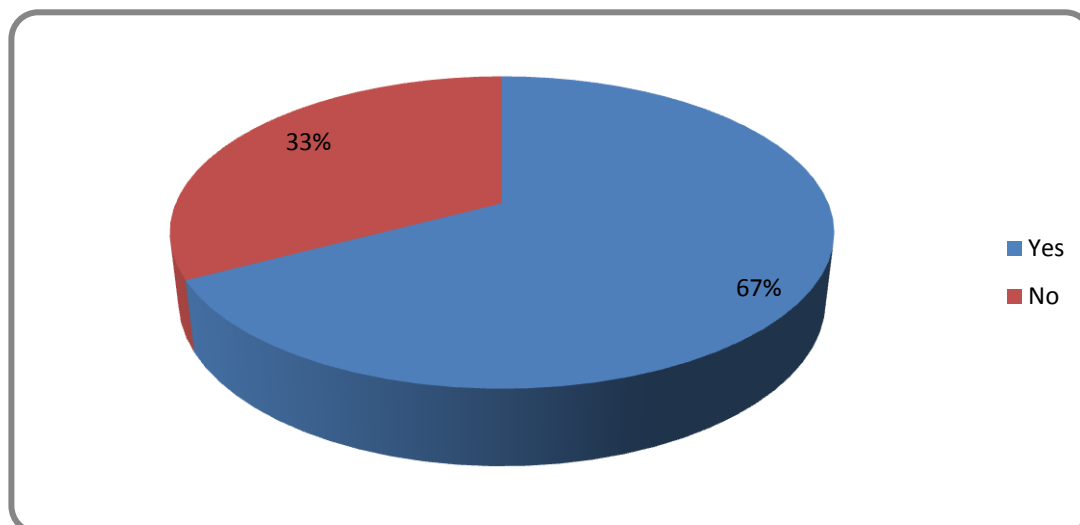
NHS	40	12.7%
Local Authority	6	29.1%
Voluntary Sector	8	20.0%
Other	1	14.5%

Figure 3 | Where do you primarily work?



Community	18	32.7%
Hospital	29	52.7%
Equally divided between community and hospital	3	5.5%
Other	5	9.1%

Figure 4 | Do you spend most of our time working with cancer patients?



Yes	37	67.3%
No	18	32.7%

APPENDIX 3 | Questionnaire Results¹⁵

Section 1: I. DIAGNOSIS AND DECISION MAKING

1. I was diagnosed early

1.a. Now

Almost always:		12.5%	7
Frequently:		44.6%	25
Occasionally:		26.8%	15
Rarely:		5.4%	3
Don't know:		10.7%	6

1.b. Two years ago

Almost always:		3.6%	2
Frequently:		30.4%	17
Occasionally:		42.9%	24
Rarely:		8.9%	5
Don't know:		14.3%	8

2. I had the information I needed to make decisions about my treatment

2.a. Now

Almost always:		37.5%	21
Frequently:		33.9%	19
Occasionally:		23.2%	13
Rarely:		0.0%	0
Don't know:		5.4%	3

2.b. Two years ago

Almost always:		17.9%	10
Frequently:		39.3%	22
Occasionally:		28.6%	16
Rarely:		5.4%	3
Don't know:		8.9%	5

3. Please give reasons to explain your answers above.

Section 2: II. TREATMENT

4. Once diagnosed my treatment and care started promptly

4.a. Now

Almost always:		44.6%	25
Frequently:		39.3%	22

¹⁵ The answers to hard-coded questions are reported here – open text questions are noted but the answers are not reported here.

Occasionally:		10.7%	6
Rarely:		0.0%	0
<i>Don't know:</i>		5.4%	3
4.b. Two years ago			
Almost always:		17.9%	10
Frequently:		50.0%	28
Occasionally:		21.4%	12
Rarely:		1.8%	1
<i>Don't know:</i>		8.9%	5

5. I received the treatment and care which were best for my cancer			
5.a. Now			
Almost always:		50.0%	28
Frequently:		35.7%	20
Occasionally:		5.4%	3
Rarely:		0.0%	0
<i>Don't know:</i>		8.9%	5
5.b. Two years ago			
Almost always:		37.5%	21
Frequently:		44.6%	25
Occasionally:		5.4%	3
Rarely:		1.8%	1
<i>Don't know:</i>		10.7%	6

6. I received the treatment and care which were best for my life			
6.a. Now			
Almost always:		32.1%	18
Frequently:		48.2%	27
Occasionally:		12.5%	7
Rarely:		0.0%	0
<i>Don't know:</i>		7.1%	4
6.b. Two years ago			
Almost always:		21.4%	12
Frequently:		51.8%	29
Occasionally:		12.5%	7
Rarely:		1.8%	1
<i>Don't know:</i>		12.5%	7

7. I was treated with dignity and respect			
7.a. Now			
Almost always:		53.6%	30

Frequently:		30.4%	17
Occasionally:		8.9%	5
Rarely:		1.8%	1
<i>Don't know:</i>		5.4%	3

7.b. Two years ago

Almost always:		46.4%	26
Frequently:		32.1%	18
Occasionally:		8.9%	5
Rarely:		0.0%	0
<i>Don't know:</i>		12.5%	7

8. Those around me were well supported

8.a. Now

Almost always:		23.2%	13
Frequently:		41.1%	23
Occasionally:		21.4%	12
Rarely:		7.1%	4
<i>Don't know:</i>		7.1%	4

8.b. Two years ago

Almost always:		16.1%	9
Frequently:		33.9%	19
Occasionally:		25.0%	14
Rarely:		12.5%	7
<i>Don't know:</i>		12.5%	7

9. Please give reasons to explain your answers above.

Section 3: III. LIVING WITH AND AFTER CANCER

10. I received an assesment and care plan at the end of my cancer treatment

10.a. Now

Almost always:		8.9%	5
Frequently:		16.1%	9
Occasionally:		23.2%	13
Rarely:		23.2%	13
<i>Don't know:</i>		28.6%	16

10.b. Two years ago

Almost always:		3.6%	2
Frequently:		10.7%	6
Occasionally:		16.1%	9
Rarely:		33.9%	19

<i>Don't know:</i>		35.7%	20
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11. I know what I can do to help myself and who else can help me

11.a. Now

Almost always:		16.1%	9
Frequently:		33.9%	19
Occasionally:		35.7%	20
Rarely:		5.4%	3
<i>Don't know:</i>		8.9%	5

11.b. Two years ago

Almost always:		12.5%	7
Frequently:		19.6%	11
Occasionally:		33.9%	19
Rarely:		19.6%	11
<i>Don't know:</i>		14.3%	8

12. I had access to wider non-clinical support following my cancer treatment

12.a. Now

Almost always:		12.5%	7
Frequently:		23.2%	13
Occasionally:		37.5%	21
Rarely:		14.3%	8
<i>Don't know:</i>		12.5%	7

12.b. Two years ago

Almost always:		8.9%	5
Frequently:		12.5%	7
Occasionally:		30.4%	17
Rarely:		33.9%	19
<i>Don't know:</i>		14.3%	8

13. I know where to get information and support following my cancer treatment

13.a. Now

Almost always:		17.9%	10
Frequently:		41.1%	23
Occasionally:		30.4%	17
Rarely:		5.4%	3
<i>Don't know:</i>		5.4%	3

13.b. Two years ago

Almost always:		12.5%	7
Frequently:		26.8%	15
Occasionally:		33.9%	19

Rarely:		17.9%	10
<i>Don't know:</i>		8.9%	5

14. Please give reasons to explain your answers above.

Section 4: IV. END OF LIFE CARE

15. I will have the right support to die well

15.a. Now

Almost always:		30.4%	17
Frequently:		41.1%	23
Occasionally:		10.7%	6
Rarely:		3.6%	2
<i>Don't know:</i>		14.3%	8

15.b. Two years ago

Almost always:		16.1%	9
Frequently:		41.1%	23
Occasionally:		19.6%	11
Rarely:		3.6%	2
<i>Don't know:</i>		19.6%	11

16. I will have the right support to die where I want to

16.a. Now

Almost always:		19.6%	11
Frequently:		42.9%	24
Occasionally:		19.6%	11
Rarely:		1.8%	1
<i>Don't know:</i>		16.1%	9

16.b. Two years ago

Almost always:		8.9%	5
Frequently:		28.6%	16
Occasionally:		39.3%	22
Rarely:		3.6%	2
<i>Don't know:</i>		19.6%	11

17. Please give reasons to explain your answers above.

Section 5: DELIVERING PERSON-CENTRED CANCER CARE

18. From your point of view:

18.a. Example 1 -- a. The challenges are...

18.a.i. Example 1 -- b. The solutions should be...

18.b. Example 2 -- a. The challenges are...

18.b.i. Example 2 -- b. The solutions should be...

18.c. Example 3 -- a. The challenges are...







18.c.i. Example 3 -- b. The solutions should be...

19. Overall, what do you think would have the **greatest impact** in helping to deliver better person-centred cancer care in Wales?






Section 6: PERSON-CENTRED CANCER POLICY IN WALES

20. Thinking specifically about cancer policy in Wales, to what extent would you agree or disagree with the following statements:







20.a. I am unaware of **national** policies which support person-centred cancer care

Strongly agree:		7.1%	4
Tend to agree:		21.4%	12
Neither agree or disagree:		12.5%	7
Tend to disagree:		17.9%	10
Strongly disagree:		37.5%	21
<i>Don't know:</i>		3.6%	2






20.b. I am aware that **national** policies exist but they are not person-centred enough

Strongly agree:		0.0%	0
Tend to agree:		42.9%	24
Neither agree or disagree:		26.8%	15
Tend to disagree:		16.1%	9
Strongly disagree:		8.9%	5
<i>Don't know:</i>		5.4%	3




20.c. I am aware that **national** policies exist but their implementation is patchy

Strongly agree:		25.0%	14
Tend to agree:		37.5%	21
Neither agree or disagree:		17.9%	10
Tend to disagree:		8.9%	5
Strongly disagree:		3.6%	2
<i>Don't know:</i>		7.1%	4

20.d. I am aware that **national** policies exist and they are well implemented

Strongly agree:		0.0%	0
Tend to agree:		14.3%	8
Neither agree or disagree:		25.0%	14
Tend to disagree:		35.7%	20
Strongly disagree:		16.1%	9
<i>Don't know:</i>		8.9%	5

20.e. At the **local level**, I am aware of policies to support the delivery of person-centred cancer care

Strongly agree:		14.3%	8
Tend to agree:		35.7%	20
Neither agree or disagree:		16.1%	9

Tend to disagree:		19.6%	11
Strongly disagree:		5.4%	3
Don't know:		8.9%	5

21. Given your answers to 20a-e, what would you like to see done about policy in Wales to ensure better implementation of person-centred cancer care in your locality?

22. Which of the following roles best defines you?

Doctor:		12.5%	7
Nurse:		28.6%	16
Allied Health Professional:		21.4%	12
Manager:		12.5%	7
Volunteer:		1.8%	1
Other (please specify):		23.2%	13

23. What type of organisation/sector do you work within?

NHS:		71.4%	40
Local Authority:		10.7%	6
Voluntary:		14.3%	8
Other (please specify):		3.6%	2

24. Where do you primarily work?

In the community:		33.9%	19
In a hospital:		51.8%	29
Equally divided between the community and in a hospital:		5.4%	3
Other (please specify):		8.9%	5

25. In which area of Wales do you work?

All Wales:		n/a	4
Anglesey:		n/a	2
Blaenau Gwent:		n/a	1
Bridgend:		n/a	5
Caerphilly:		n/a	3
Cardiff:		n/a	14
Carmarthenshire:		n/a	3
Ceredigion:		n/a	1
Conwy:		n/a	4
Denbighshire:		n/a	4
Flintshire:		n/a	5
Gwynedd:		n/a	2
Merthyr Tydfil:		n/a	5

Monmouthshire:		n/a	1
Neath Port Talbot:		n/a	5
Newport:		n/a	3
Pembrokeshire:		n/a	1
Powys:		n/a	5
Rhondda Cynon Taf:		n/a	4
Swansea:		n/a	9
Torfaen:		n/a	2
Vale of Glamorgan:		n/a	4
Wrexham:		n/a	9
Other (please specify):		n/a	2

26. Do you spend most of your time working with cancer patients?

Yes (If yes, please answer questions 27 and 28):		66.1%	37
No (If no, please click 'Continue' to complete the survey):		33.9%	19

27. What is your specific role in relation to cancer care?

Surgeon:		2.6%	1
Physician:		5.1%	2
Specialist Nurse:		33.3%	13
Allied Health Professional:		23.1%	9
Other (please specify):		35.9%	14

28. What type of cancer do you primarily deal with?

Breast:		n/a	20
Lung:		n/a	19
Colorectal:		n/a	13
Haematological:		n/a	11
Upper GI:		n/a	12
Head and neck:		n/a	15
Urological:		n/a	13
Skin:		n/a	13
Sarcoma:		n/a	10
Gynaecological:		n/a	13
Thyroid:		n/a	9
Brain:		n/a	13
Other (please specify):		n/a	12

APPENDIX 4 | Interview Informants

We are grateful to the following for information and advice:

Sue Acreman

Rhian Dash

Baroness Ilora Finlay

Dr Simon Gollins

Dr Bridget Gwynne

Dr Jane Hanson

Damian Heron

Phil Jarrold

Dr Chris Jones

Dr Matt Makin

Professor Tim Maughan

Linda McCarthy

Hywel Morgan

Fiona Peel

Bernadine Rees

Sue Roberts

David Sissling

Veronica Snow

Glynis Tranter

Dr Richard Walker

Professor Clare Wilkinson

The following questions formed the basis of the discussion agenda but the individual interviews were led by the responses of our informants.

What is person-centred cancer care?

The rationale for asking this was to better understand across a number of stakeholder groups how person-centred cancer care is understood and defined in practice.

- From your point of view how would you define person-centred cancer services?
- What kinds of things would people experience in such a service?
- How would it differ from what is currently delivered?
- How do you know when you've achieved excellent person-centred care?

How much person-centred care do you deliver?

The rationale for asking this was to better understand the 'spread' of person-centred care currently and to identify good practice.

- According to your definition, how far is person-centred care currently being delivered?
- According to Macmillan's definition, how far is person-centred care currently being delivered?
- How do you account for any difference between these two amounts?
- To what extent is your service 'person-centred' across the entire pathway of care (from diagnosis to end of life) and across different professionals?
- How geographically equitable are person-centred services across the communities you serve?

What's stopping you doing more?

The rationale for asking this is to better understand the barriers for change and what could be done about them. A further rationale would be to ask about the role that Macmillan could play – but only if this was considered to be useful.

- Is there a clear vision for cancer services in Wales?
- What support would you need to make more person-centred care a reality?
- What would need to change and how might the change be brought about?
- In the current economic context, to what extent does existing policy and/or practice hinder the delivery of person-centred services? How could this be changed?
- What should be the first priority for change?

How important is it that person-centred services are cancer specific?

The rationale for doing this was to better understand the specificity of cancer services and its overlaps with other more generic forms of care.

- WAG recently announced new standards requiring every cancer patient to be allocated a nominated key worker who will be responsible for co-ordinating their care. What will be the issues for your service in implementing these? What do you see the new key worker encompassing?
- Given the range of possible priorities, how important would you consider delivering person-centred care to be?
- How far should person-centred cancer services be different from other chronic conditions?

APPENDIX 6 | Members of the Expert Steering Group

Mary Cowen, Chairwoman, Chronic Conditions Alliance, Arthritis Care Cymru

Tina Donnelly, Director Royal College of Nursing, Wales

Gill Evans, Chairwoman North Wales Cancer Network Patients Council

Carol Lamyman-Jones, Director, Board of Community Health Councils in Wales

Matt Makin, Chief of Staff, Betsi Cadwaladr University Health Board

Rev Eldon Phillips, Chairman, South Wales Cancer Network patients Council

Martin Semple, Deputy Director, Royal College of Nursing, Wales

David Sissling, Chief Executive Abertawe Bro Morgannwg University Health Board

Dr Jon Skone, Director of Social Services/County Director, Pembrokeshire County Council/Hywel Dda LHB

Viv Sugar, Chair, Consumer Focus Wales

Kate Watkins, Director, Wales NHS Confederation

Clare Wilkinson, Professor of General Practice, Cardiff University

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