

A critical reflection on the challenges and benefits of conducting community-engaged research: working with community-based researchers and organisations

A short working paper to accompany the Final Report of *In Their Own Words: A pilot study to elicit perceptions of dignity and dignified care from a purposive sample of African-Caribbean and Black Welsh people aged 50 years and older living in Wales*

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Introduction

Dignity can be understood to be a multifaceted concept, which draws upon a person's sense of identity, autonomy and human rights and is shaped by a number of social markers such as ethnicity, gender or class. Dignity is commonly understood to be a key factor in the delivery of good quality health and social care. Over the decades research in the area of dignity and age has grown in both the UK and internationally. Although the body of research evidence has helped significantly to refine the concept of dignity and to broaden the understanding of older people's experience of dignity in care, few studies have sought to:

- examine the concept of dignity and perceptions of dignified care as linked to personal identity and social identity and racialisation;
- develop an understanding of the possible impact this has on enhancing or damaging a care encounter.

This exploratory study is motivated by the fact that the number of older people in Wales, including those from Black and minority ethnic (BME) backgrounds, is set to steadily increase and that policies for older people in Wales, and the research evidence underpinning them, will have to reflect, and seek to provide effective services for, Wales' increasingly diverse older population. The aim of the study was to:

- explore older people's experiences of care in order to bring conceptual and practical clarity to the concept of dignity (and associated indicators);
- test methods of accessing the views and experiences of older people from BME communities.

The aim of this summary report is to provide a commentary on

- the formal cross-sector partnership that was established with a community-based anti-poverty organisation at the start of the study;
- the value and contribution of working with community researchers;

- the value, and experience of consulting with members of the targeted population groups.

A review our community engagement work may yield recommendations that could be considered by other researchers when conducting research in an urban, multi-cultural and multi-ethnic research context. It is also of worth to note that, this report builds on earlier reflections on community-based research and engagement work (Saltus 2006) and will be, in part, framed in the context of the eight categories or dimensions that Meleis (1996) proposed as essential for evaluating methodological rigour in research and scholarship: contextuality, relevance, communication styles, the awareness of identity and power differentials, disclosure, reciprocation, empowerment and time. The study presented an opportunity to explore what other dimensions may need to be considered when working with minoritised groups in general and older people and elders from particular minoritised background in particular.

Note on Terminology

Older people: In this report older people are adults aged 50 years and older, as defined by the *Wales National Strategy for Older People* (2008).

Racialised groups: The concept of race has been a pervasive force in the development of modern western society. Although found to have no biological basis, what we know as race can be defined at its most basic level, according to Winant (2000), as a concept that signifies and symbolises socio-political conflicts and interests in reference to different types of human bodies (p. 172). Accordingly, racialisation is the process by which people and groups of people are ranked on the basis of their presumed racial differences and the attendant meanings of such differences in particular contexts. The process has long been contested and problematised. The focus of the study is on two particular population groups: African-Caribbean or Black West Indians, and Black Welsh.

Black and Minority Ethnic (BME) groups: In the UK, the terms 'minority ethnic' or 'ethnic minorities' are most often used to refer to all minority groups of the population not indigenous to the UK that hold cultural traditions and values derived, at least in part, from countries of their or their ancestors origin. The term 'black' is often used not to differentiate black minority groups from other minority ethnic groups, but rather to ensure that the continuing impact of the legacy of racism remains highlighted and is made problematic. The term 'black and minority ethnic' (*BME*) people, populations and groups will be used in this summary, with key minority ethnic groups identified according to those included in the UK census classification system. It is axiomatic that BME populations are heterogeneous, with differences both within and between groups.

Ethnicity: A fluid, shifting and dialectical *process* through which collectivities of people negotiate the social world. In the course of time groups identify themselves (or are identified by others) with reference to characteristics such as language and cultural practices and transmit this information down the generations. Sometimes a territorial claim is involved (Olumide 2002, p.31)

Community-Engaged Research

Communities continue to play a pivotal role in modern societies and community-focussed approaches to policy development and to research are recognised increasingly as key to addressing some of the seemingly intractable social and economic challenges we face not just in Wales, but throughout the UK. Thus, research that involves members of the public in of how it is conceived, designed and implemented is being promoted increasingly as good practice by research funders and other stakeholders (Evans et al, 2011). For it is believed that this approach has the potential to address relevant issues that may impact people's lives more positively in terms of realising better outcomes for them and to empower them to become part of that process (Evans et al, 2011).

Community research works to acknowledge and address a number of challenges and conventions. For one, there is an acknowledgement of power differentials that can often emerge in working relationships that are characterised by hierarchy and where institutions and individuals within institutions adopt the role of the 'expert'. Such power imbalances in working structures and relationships impede the development of trust, which is a fundamental prerequisite for establishing effective research partnerships. Furthermore, if the locus of power in terms of decision-making, funding, resources and project management is situated within academic institutions, they are in a much better position to be able to control the project and impose their will on community partners (Sullivan et al. 2001). This may lead community members to feel that their contribution is merely tokenistic rather than meaningful. Moreover, Resnik et al. (2010) make the point that scientific interests held by most researchers may not be compatible with community interests and this may give rise to conflict between the research partners.

A key element of community research is working with communities and with community researchers to develop and to foster trust, to work through differing priorities and expectations, and to ensure that participants and members of the public engage in research as co-producers of knowledge. Furthermore, for marginalised or discriminated population groups, a community-based research approach may be more sensitive to their circumstances, needs and perspectives than more traditional research approaches (Shoultz et al. 2006). Our understanding of community research is that it must be co-produced; the role of the university-based academic is to bring together community knowledge, to make it visible to a wider audience, and to work with research participants and researchers to find ways to practical uses of the research findings.

Community-based research is rooted in finding ways of working collaboratively with groups of people affiliated by cultural or ethnic affinity, as well as by geographic proximity or special interest, to address issues of importance to them. This approach is underpinned by the expectation that researchers find ways to conduct research that is of direct relevance to

population groups, and to involve actively members of the public and service users in research activities way beyond that of being passive participants or research subjects.

The model of engagement developed in this study involved collaboration with Ethnic Minority Communities First Cardiff, community-based organisation, whose staff has extensive experience of working with a range of minority ethnic groups, organisations and individuals. We also recruited two community-based researchers who brought to the study their extensive experience of and links to the targeted population groups.

The Ethnic Minority Communities Programme (Cardiff Communities First)

Communities First is the primary Welsh Assembly Government funded community development programme in Wales. Launched in 2002 it was initially targeted towards the 100 most deprived wards as defined by the Wales Index of Multiple Deprivation. It was later expanded to include more areas including sub-wards and communities identified by a common issue . The latter are referred to as ‘communities of interest’ and includes BME communities in both Cardiff and Newport.

The Ethnic Minority Communities (EMC) Programme is one of 12 programmes based in the city of Cardiff; however it is unique in two important respects:

- it focusses on ‘communities of interest’, namely BME communities, rather than being focused on communities defined by their ward or sub-ward status;
- it is also city-wide and therefore it has the potential to work across all neighbourhood management or electoral wards throughout the Capital.

In *The Community Development Framework for Community Development in Wales* (2006) community development is defined as:

(A) process through which local people engage and enact change in local communities. It has a role in achieving equal opportunities, accessibility, participation in democratic processes and sustainable economic, social and environmental change. (p.4)

EMC works towards this aspiration by championing the 'bottom up' approach which seeks to utilise the services, experiences and insights of local people to inform programme and service development and delivery.

EMC is a multi- practice, community-based organisation. The main areas of work undertaken by the EMC are: (i) providing specialised and culturally sensitive services to stakeholders, (ii) empowering individuals, groups and organisations through information exchanges and capacity building, and (iii), addressing race inequality and promoting social justice in Wales through a range of programmes and initiatives. This is evident in its core activities: a volunteering and work placement scheme, a package of information, consultation and training services delivered across a range of sectors, community development, social cohesion and outreach work, as well as a specific programme of work linked to health and wellbeing.

Of added value is the fact that EMC conducts and commissions small-scale research to underpin key strands of their programme of activities, and in addition, facilitates a number of consultations and focus groups, primarily in partnership with local and regional Welsh universities. This includes:

What are multi-purpose community organisations?

These are organisations, based in a local area, that offer multiple services, activities and facilities to local people. They are engaged in the social, economic and environmental wellbeing of the area, often working alongside other organisations in the public, private and voluntary and community sectors. Typically, they are located in a building which is open to local people and may also host other community groups and organisations.

Baker et al. 2011, p.3

- *Black & Minority Ethnic Communities Consultation Report (2005)*
- *Mapping of Employment Services Targeting Minority Ethnic Communities in Cardiff (2008)*
- *Real Opportunities for Learning & Employment (ROLE) Evaluation Report (2009)*
- *EU Roma Communities in Cardiff – Needs Analysis Report (2011)*

Moreover, in keeping with the aspiration for all Communities First programmes to be community lead, all programmes were required to establish Local Partnership Groups (or Local Partnership Boards). These cross sector partnerships comprise community members and service providers from voluntary, business, statutory and public sectors with majority membership (up to 1/3) being the community representatives. Thus, BME communities in Cardiff have a direct access to service planners and deliverers and play an explicit role in shaping action plans for EMC staff. Of equal importance is the fact that EMC has an extensive community resource inventory of contacts and well established links with key stakeholder groups and representatives.

Conducting community-engaged research: the role and contribution of multi-purpose, community-based organisations

As detailed above, conducting community-engaged research is not without its challenges, however, the involvement of community-based organisation such as EMC can add value and offer insights that may not be apparent to those with less experience or knowledge of particular community groups (be they ethnic groups, neighbourhoods/locales, or another group brought together by a common interest). It is axiomatic the community-based organisations are most often seen as key access points to particular population groups. Although this is quite important, community-based organisations play other equally valuable roles. First, in working with EMC, the preoccupations of the organisation (social justice, social cohesion, empowering and capacity building) were continually spotlighted and helped to keep us mindful of some of the tensions that exist between local communities and research communities which may hinder recruitment and participation.

Second, the focus of multi-purpose organisations such as EMC on community development, cohesion and engagement lends itself to not only a community-based research approach but also provides a sharpened focus on practical approaches to engagement and the need for practical solutions. This makes it important to continually reflect on the methodological and theoretical framework of community-engaged approaches to research. The role of critical reflection and the importance of embedding flexibility into the research process are vital when resolving tensions that may arise in the differing approaches to engagement promoted in academia and by the community and voluntary sector.

Lastly, organisations such as EMC have developed, over an extended period, rich networks and cross-strand links that allow such organisations to work across the public, voluntary and private sectors, establishing thematic networks and collaborations with a range of practitioners and professionals across the sectors in ways that work to align policies and practice, and to create bridges between communities and services. These links and networks are invaluable tools that are shared with trusted partners, including research partners.

The role and contribution of community researchers

For a growing number of academic-based researchers, the involvement of community researchers is an important element of community-based research. Community researchers (CRs) are people with a detailed understanding of a particular local community who use their knowledge and networks to foster trust and encourage recruitment, to facilitate data gathering and to support the dissemination of findings. They are local people who have an in-depth understanding of a particular community or locality and strong social networks. For the study, two community researchers were recruited to develop the data collection tools and to gather data. Both researchers had extensive links with the targeted sample, and have worked extensively with,

and been a part of, community groups and organisations whose membership comprise primarily, African-Caribbean and Black Welsh people.

As discussed in a previous study (Saltus 2006), the role of community researchers does not guarantee the success of a study, nor does it address the recruitment, involvement and retention issues that may arise in conducting research with seldom heard groups. However, as expected, the work of the community researchers proved invaluable. First, their involvement made the study visible to local people and was vital to building trust and familiarity with key community informants, who in turn, cascaded information on the study throughout their networks.

Second, their knowledge of the local context allowed for the specificity within and between the target groups to be highlighted which led to our being able to from different sections of the population group (for example, by targeting faith and community groups and linked networks, and by working with them independently). Third, working with the community researchers brought the added dimension of critical reflection to the key stages of the research process, with the community researchers developing and piloting the research questions, and developing bespoke recruitment and promotion strategies (e.g., taking leaflets to churches and community centres, and making use of their mailing lists to contact potential participants).

Also of importance was the issue of locality, of utilising spaces familiar and known to older people was not only highlighted by the community researchers but, based on their established connections with the target groups, such

For a community that is often overlooked, I think projects like this one allow people the opportunity to have a say and feel like they have contributed to services that are aimed at them. Using community researchers is a good way of engaging and gathering information from the community because you have already established with them a relationship; they trust you..

All the people I interviewed were sceptical about the study and what was required of them. But at the end of each interview all the participants commented on how much they thoroughly enjoyed taking part. I thoroughly enjoyed taking part in this study; everyone has a story to tell and I enjoyed listening.

Edna Esprit-Griffiths
September 2011

spaces were secured and used to promote the study and also used as a venue to conduct the interviews and discussion groups. Two points can be made regarding the data collection process. First, there is the confidence and competence gleaned by the CRs from having been successfully involved in key stages of the study and second, the shift in power or control in favour of the community researchers which allowed for a more fruitful engagement with the members of the targeted population groups.

Lastly, the community researchers kept an important point alive: the missing and potential problematic elements of the study. Issues such as the relevance and applicability of the interview aids (in this case a series of photographs and a series of phrases on cards), the fact that certain sections within the target populations groups were not being becoming involved, as well as feedback – both negative and positive - that they received.

Discussion groups with Caribbean women elders

The group discussions were organised prior to the recruitment activities in order to introduce people to the study but, more importantly, to consult on how best to conduct this study. Although not a planned stage of the original research proposal, after some discussion, it was felt that more work needed to be made to recruit men and women of African-Caribbean background.

Community and faith groups known to the CBRs were contacted and members of two groups agreed to share their views. There were two

I was surprised how much I enjoyed conducting the study. There is an awful lot of research that needs to be done and moreover, there is a lot that Black people have contributed to Wales that needs to be unlocked. I was able to involve people that are not normally accessible – the ‘seldom heard’. I am not sure if the Welsh Assembly Government or others realise the extent to which older Black people are excluded – their voices are not heard and this needs to be addressed.

You need community researchers to get to those people, to draw out their voices and to make sure their views and experiences are heard, acknowledged and feed into policy and practice. I would like to get more involved in researcher in the future. I want to be able to explain to people the benefits, as well as the limits to research. People think research brings about instant change – that’s not the case! It’s about building better lives for people in the future.

*Pauline Andam
August 2011*

discussion groups. The first group meeting took place in April 2011 and was held in a local church hall. The luncheon was organised by the one of the community researchers. Eight older women attended the first meeting, the majority of whom are in their mid to late seventies. The questions that were asked are as follows:

- *What do you think about the study?*
- *What are your feelings about being asked to help develop this research?*
- *Have you been interviewed for a research study before? What was it like?*
- *I am working with a number of people who are community-based researchers and community development practitioners (Pauline Andam, Edna Esprit-Griffiths and Tony Hendrickson who you all know). They work closely with Caribbean older people on a regular basis. What do you think about this?*
- *How do we tackle sensitive or personal issues? We want to talk about how people engage in social services and this may be considered a sensitive issue for some people. How would you advise us to approach this with people like yourselves? What would it take for you to feel comfortable talking about these and other issues?*
- *If you were to be interviewed, would you prefer to be interviewed by a stranger or someone you know? Does it make a difference? How would you expect to be treated?*
- *We want to capture stories. What are your views on this? Is this something you think older people like yourselves would be interested in doing? What would you expect from us?*

The second meeting took place in June 2011 and comprised a presentation by one researcher participant, followed by a very short question and answer

session, the exchange of other possible participants, and the scheduling of interviews with the attendees. Eight women attended the second luncheon.

Learning points

In both meetings, field notes were made; in the second meeting, the presentation by the participant was captured audio-visually and transcribed verbatim (see side bar). What follows are the key summary points raised by the attendees.

- The act of involving in key stages of the research process potential participants or people who are the focus of your study was considered vital, especially when working with older people.
- Older people from the Caribbean have important insights to share. They have played a valuable role in the development of Welsh (and UK) society, and their views and experiences, their voices should not be marginalised; they should be acknowledged, respected and accepted.
- This particular group has been involved in research and scholarly activities in the recent past. They enjoyed being involved but were still awaiting, in some cases, to receive information on the findings.
- The role of community-based researchers and community development practitioners is vital. It provides university-based researchers with a key point of access. The acceptance and involvement of people trusted and respected by the local African-Caribbean community engenders interest and engagement. The involvement of 'known and trusted' people is especially important for older people and elders. Likewise, conducting interviews in known and 'safe' public places like a community centre where groups already gather regularly, as well as conducting interviews as part of an established social gathering (for example, before and after a scheduled luncheon) encourages involvement and recruitment.

- One's 'approach', which is taken to mean how one approaches, talks to and engages with a person- which is itself a dimension of dignity and respect – was the overwhelming response to the question 'how do we tackle sensitive or personal issues?' Taking time to make a person feel comfortable, being aware of how you (the researcher) are coming across and impacting on the person, and providing a full justification of why the questions were being asked were also raised as important issues to consider when seeking to explore potentially sensitive issues.
- Another emerging theme was the importance of maintaining one's privacy and self-respect, and the importance of shielding family members, protecting them from changes in an older person's or elder's personal circumstances that may cause family members to worry. For example, older people tend not to discuss with family issues such as the need for help around the house, or a troubling physical condition. Although there was a general consensus that an interviewer who was already known to the participants would be an important consideration, it was also acknowledged that for some people it was better that there was no or limited connection between the interviewer and the interviewee so as to facilitate greater disclosure of personal circumstances, experiences and expectations.
- There was a general consensus that capturing stories was a good idea and would allow for the voices, the faces and the expressions of older people to be captured.
- The impact of research was raised. What will come out of this research? This speaks to the problem of conducting research that does not then impact on policy and practice.

Conclusions and Recommendations

In developing a summary of best practice, the framework put in place by Meleis (Saltus 2006) that highlights eight criteria for culturally competent scholarship and research as detailed below, remains a good starting point.

Meleis' Eight Criteria for Culturally Competent Scholarship and Research

Criterion	Definition
1. Contextuality	Knowledge of participants' lifestyles and historical and socio-political circumstances
2. Relevance	Research topic/question is significant for the health of the target population(s) and for nursing
3. Communication Styles	Understanding of participants' preferred language, idioms and speech patterns
4. Awareness of identity and power differentials	Investigators' cognisance of distance and inequality in power and status inherent in the research situation.
5. Disclosure	Recognition of issues related to trust, secrecy, and privacy for participants
6. Reciprocation	Researchers and participants achieve some benefit or desired goal from the research
7. Empowerment	Participants receive some lasting sense of control over a problem, or skills for improving health
8. Time	Research team is aware of group's perspectives on time and accommodates them

From this study, several recommendations to improve future, local, community-based research projects can be made.

- **Impact:** Early involvement of community partners and members in the direction and design of the project will facilitate not only acceptance and support, and create a greater understanding among researchers of the needs and priorities among communities but can also work to ensure that the study design is appropriate. The need for flexibility is key since community partners and members may not want to be involved in the full research process and meaningful options, and the ability to opt in and out of the various stages should be considered.

- **The role of fostering engagement and trust:** The forming of trusting relationships was described as pivotal to the successful recruitment of minority ethnic groups into research. This takes time.
- **A range of approaches:** Personalised approaches (word of mouth, inclusion in existing programmes of outreach and support) are likely to be better received than more impersonal written approaches. It is important to make use of a range of approaches and to provide information in a range of formats.

- **Addressing ‘research fatigue’:** To develop meaningful partnership and collaboration between researchers and communities, particularly with population groups that have experienced societal discrimination or who face multiple deprivations, it is important to be cognizant of and acknowledge the ‘research fatigue’ felt by some and the need to be very clear about the role of research in influencing and making real, practical change in the short, medium and long term.

- **Addressing potential resistance:** To develop meaningful partnership and collaboration between researchers and communities, it is important to be cognizant of and acknowledge the history of sometimes negative encounters between researchers and communities, and the impact this has on recruitment and participation. Develop a community-engaged outreach and recruitment strategy.

The role of community researchers

- Can allow for a narrowing of the gulf between academia and community settings, perspectives and approaches to research;
- Provides a critical view of the methodological appropriateness underpinning the study;
- Makes visible and seeks to shift power/control in favour of the Community Researchers;
- Creates a link between the university-based research members and the targeted, community-based population groups;
- Increases the researchers' confidence and competence
- Creates stronger links between research and grass roots activity
- Provides the research team context-related information.
- Provides a critical perspective of the impact the study is making on the participants

- **Returning the findings:** keeping all those who take part in research informed and disseminating the results is an established element of high quality research. Undertaking research and returning the findings to community members (including those who took part) can build a sense of ownership of the research, reduce 'research fatigue' and help foster trust and meaningful engagement.

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