Research paper

A critical reflection on the research priorities for improving the health and social care to black and minority ethnic groups in Wales

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ABSTRACT

Conceptual issues such as *race and ethnicity*, socio-economic status and geographic location impact significantly on the level of access to information and on the utilisation, experience and satisfaction of health and social care provision. In Wales, devolution has opened up new opportunities for assessing and addressing equality issues. In addition, policy shifts in Wales have led to a formalised amalgamation of health and social care policy making. It is within the context of these constitutional and policy changes that national research and support frameworks rooted in the health and social care needs of black and minority ethnic (BME) groups are being mapped.

The aim of this paper is to detail one aspect of the findings of a scoping study conducted in 2005: the perceived priorities for and the challenges of improving the health and social care of black and minority ethnic (BME) groups in Wales. By reflecting on the main themes that emerged from the study, this paper offers a reflection on the national context within health and social care strategies for people from BME communities.

Keywords: black and minority ethnic (BME) groups, devolution, evidence-based research, health and social care, Wales

Introduction

The emergent research and development agenda in Wales on black and minority ethnic (BME) health and social care issues must be placed in the context of constitutional change. Chaney and Drakeford (2004, p.16) have referred to the devolved administration as essentially a 'social policy Assembly', indicating that in the areas of education, health, housing and social services responsibility is now entirely devolved to Wales. This significant shift in the locale of policy making is accompanied by a strong political rhetoric

that speaks of 'Made in Wales' policies and 'framing policies tailored to Welsh needs' (Welsh Assembly Government (WAG) 2003a, pp.1 and 11) and by an impetus to become 'a country that develops its policies on the basis of evidence, and that has mechanisms in place to improve the health and social care of the people of Wales' (WAG, 2002, p.4). The vision for the WAG's strategic agenda is for a fairer, more prosperous, healthier and better educated country (WAG, 2003a), and key to this was the merging of health with social care resulting in the recent creation of the Health and Social Care Department and the appointment of a Minister for Health and Social Services.

There has been considerable debate as to the extent to which policy in the devolved nations does and will diverge from other parts of the UK (Mooney *et al*, 2006) and particularly in relation to health policy (Greer, 2006). Since its inception the WAG has steadily gained increased powers with a total of 24 Acts granting powers to the Assembly in 2006. Now in its third term, the granting of primary legislative powers under the Government of Wales Act 2006 will usher in a strengthened indigenous policy-making process to complement the policy levers it has used to date. One area where Wales has a unique profile, by comparison with elsewhere in the UK, is with regard to the equalities. Equality of opportunity is identified as one of three cross-cutting themes permeating policy making in the new government. Central to this is the statutory duty enshrined in the Government of Wales Act (1998) that states that 'the Assembly shall make appropriate arrangements with a view to securing that its functions are exercised with due regard to the principle that there should be equality of opportunity for all people' (Section 120). This equality imperative applies to *all* the devolved functions of government in Wales. This duty, Chaney and Fevre (2004) argue, is unique and represents a significant divergence from equality laws in operation in other parts of the UK, not least because it modifies all Westminster statutes, where the Assembly has powers, in their implementation. As Chaney and Fevre (2004) suggest, the merits of the 'Welsh model' equality duty are based on the fact that it is *all embracing* in scope, requires government to be proactive in all equality matters and conveys legally enforceable rights. Coupled with the requirements of the Race Relations (Amendment) Act 2002 relating to the UK, this statutory framework suggests a strong equalities context within which to develop health and social care strategies for people from BME communities.

The context: what is known about the health and wellbeing of BME groups in Wales?

In view of the changes outlined above, the need to address the multiple threats to the health and social wellbeing of a diverse population has taken on some urgency. In terms of the health of the general population, Wales' record is by any measure poor. It has some of the worst child poverty rates in Europe (Bradshaw, 2002). In the last census 12% of people in Wales reported that their health had been 'not good' over the past 12 months and almost one-quarter (23%) reported having a limiting long-term illness or disability which restricted their daily activity (Office of National Statistics, 2001). Wales comprises some of the most deprived regions in Europe, and huge inequalities in health outcomes exist for the most deprived communities. Wales has a BME population of just under 62 000 (2.1%) out of a population of approximately 2.9 million people (www.statistics. gov.uk). It is important to note that its long history of minority ethnic settlement and the diverse nature of the histories, settlement patterns, residential status and occupational profiles of BME groups in Wales suggest it is markedly different from other parts of the UK (Williams *et al*, 2003). For example, the ethnic profile and socio-economic status of BME individuals from the more rural north of Wales are markedly different from those in Cardiff (Williams *et al*, 2005a), as are the issues of access to healthcare that they face (Williams *et al*, 2005b). In addition, factors of considerable diversity and dispersal have meant that natural or politicised collectivities have not arisen in articulating health needs as has happened in other parts of the UK. Such distinctiveness, it is argued, suggests specific responses tailored to need within the country.

Moreover, in their analysis of devolution in Wales, Williams *et al* (2003) have argued that devolution represents an opportunity to shift from a *laissez faire* approach to a structured programme of nationally responsible policies. The distinctive lethargy and subsequent legacy of neglect of race equality issues in Wales, however, has hampered development in Welsh institutions in as much as there has been a paucity of statistical evidence, with many public bodies having developed idiosyncratic approaches to ethnic auditing and monitoring. In addition there has been a dearth of research studies, with those that have been available 'being small scale, parochial, lacking in methodological rigour and contributing little to vigorous theoretical

debate' (Williams *et al*, 2003, p.142). Recent Welsh studies have sought to identify the health promotion needs of BME groups in Wales (Papadopoulos and Lay, 2005); the mental health information and treatment needs of BME groups in Cardiff (Saltus and Kaur-Mann, 2005); the experiences of carers from BME backgrounds (Welsh Assembly Government, 2003b); the health and social care needs of unaccompanied children seeking asylum (Hewett *et al*, 2005); and BME communities' needs and experiences in accessing legal and related social welfare advice services (Williams *et al*, 2005b). A few studies have been undertaken that focused exclusively on specific groups, for example on the experiences of Bangladeshi patients in primary care settings (Hawthorne *et al*, 2003), the care needs of elders (Patel, 1994), and support needs of Bangladeshi carers (Merrell *et al*, 2005).

Despite this important research activity, it is evident that much more work is necessary. In his recent systematic review, Peter Aspinall (2006) identified the major gaps in national Welsh studies, such as the Welsh Health Surveys, and the unreliability of ethnicity data, for example the Patients' Episode Database for Wales (PEDW), in highlighting the needs of BME groups. More recently, both the Welsh Assembly's *Strategy for Older People in Wales* (2003c) and the document on child poverty in Wales *A Fair Future for our Children* (Welsh Assembly Government, 2006) note the dearth of reliable data on ethnicity to guide policy making in these areas. In her review, entitled *Health, Well-being and Access to Health and Social Care of Selected Minority Groups* (2004), Vivienne Walters highlighted the apparent lack of information and access to care for BME populations in Wales. Key issues of concern included the lack of appropriate information, language barriers, culturally alien services, and institutional discrimination – issues that are mirrored by the research findings of studies conducted elsewhere in the UK (Modood *et al*, 1997; Arai and Harding, 2002).

The aim of the scoping study and methods of data collection

This paper examines one aspect of the findings of a scoping study conducted in 2005, the findings of which were further tested throughout 2006 in a series of focus groups and stakeholder meetings. The particular aspect of the 2005 study explored in this paper is the perceived priorities and the challenges of improving the health and social care of BME groups in Wales as understood by key stakeholder groups. By reflecting on the main themes that emerged from the study and subsequent consensus-gathering work, this paper offers a framework for future appraisals and seeks to identify some of the key issues raised by such network-based approaches to research, policy and practice development.

A short questionnaire was developed and piloted with a sample of academics, health and social care service providers and voluntary agencies working with BME groups. The questionnaire comprised six questions which explored the following topics: health and social care issues affecting BME groups; research priorities and challenges affecting research on the health and social care of BME groups; opportunities and expectations of a research and development network and views on the way forward in developing the network. The sample was purposive, with snowballing technique/reference sampling also employed. The inclusion and exclusion criteria reflected the aim of developing a sample of BME service users, patients and members of the public, staff working in voluntary and statutory health, social care and social welfare settings who worked with a significant number of people from the targeted BME backgrounds as well as academics working in Welsh universities. Following established ethical guidelines, all participants were informed as to the purpose of the study and were assured of confidentiality. All data were anonymised and stored securely. Funding constraints meant that the research instruments were designed to be delivered in English only.

The research team and 23 co-workers disseminated the questionnaire to their networks and service user groups via meetings, email correspondence, and telephone exchanges. The questionnaire was also distributed by email discussion group managers to relevant discussion groups. Data were collected between March and April 2005. The questionnaires to stakeholders in academic, NHS, and voluntary health and social care sectors yielded 142 responses (see Table 1), and gave evidence from service users, practitioners and researchers about their perceptions of research priorities.

In April 2005, three consensus focus groups were also held, the aims of which were to: provide the opportunity for team members to present and summarise the responses to the questionnaires, reach a consensus regarding the key issues raised in the responses and scope the way forward. Summaries of the responses from the questionnaires and notes from the focus group discussions were produced. The size of the consensus focus groups varied from three to 13 participants, and the same inclusion/exclusion selection criteria were used.

Findings

The key themes emerging from the questionnaires and developed further in the census group discussions are

Table 1 Responses from stakeholders

Stakeholder group	Number of responses
Staff – voluntary sector	28
Service users – voluntary sector	29
Staff – NHS trust	19
Staff – Welsh university	37
Staff – local authority	8
Staff – local health board	6
Staff – equalities organisations	5
Community group representatives	2
Other 5	5

Total = 139. Data were missing from three questionnaires.

organised in such a manner as to reflect some of the key issues highlighted by these interested parties. Further analysis of the findings of this study, together with the findings from subsequent data gathering and consultation exercises conducted after the study, throughout 2005 and 2006, will not be discussed in this paper. What the following section provides is a snapshot of some of the key research priorities and challenges that emerged from the scoping study (see Box 1).

Key priorities

The first theme that emerged from the data was the concern regarding illness at different points in the life cycle, including postnatal depression, services for children and young people and the health of BME elders. Concerns about a lack of information and understanding, for example of women in their middle years, and the training of residential care home workers about the needs of BME users were expressed.

A second theme identified was illnesses either specific to BME groups or with a higher incidence in BME communities. The majority of respondents listed coronary heart disease, hypertension, diabetes and haemoglobinopathies (such as sickle cell anaemia) as well as some cancers. In all the focus groups, mental illness was identified as a key concern, and in one focus group there was a strong emphaisis placed on the treatment of sexually transmitted diseases.

As well as specific illnesses, the findings revealed a concern with specific problems associated with particular social groups, for example, asylum seekers' unfamiliarity with health and social care provision, post-traumatic stress disorder and malnourishment. For Travellers and Gypsies, questions of eviction, homelessness and poverty have implications for health and wellbeing. Racial discrimination and institutional racism against asylum seekers, Gypsies and Travellers were important concerns.

A fourth theme identified was the broader determinants of health and wellbeing, including housing, poverty, racism and education. This related to a further set of priorities regarding access to services. In particular, a lack of translation and interpreter services was felt to be a key factor influencing access to social and healthcare services and information. The need for appropriate health promotion programmes was highlighted as a key issue, along with encouragement to participate in the various screening services which, although available, have a very low take-up rate among BME groups. These factors of course are similar to the concerns of other parts of the UK.

A fifth theme was the need to develop culturally sensitive services and the importance of increasing staff knowledge and competencies through training. As one respondent wrote:

> 'Cultural awareness does not always lead to cultural competency. There is a need to address the education and training of those providing services'.

Box 1 Key research priorities and challenges

Key priorities
- Research focus on health and wellbeing throughout the life span
- Research on the illnesses that affect members of BME groups to a disproportionate extent
- Evidence base of the impact of broader determinants of health and wellbeing
- Strengthening the role of the BME voluntary sector
- The development of effective workforce development strategies to build the capacity and responsiveness of the needs of multi-ethnic and multicultural population groups

Key challenges
- Promoting user involvement and community engagement in the formulation of research agendas
- Effective sharing in Wales of knowledge and good practice around particular interventions
- Addressing the needs of BME populations in rural areas

There was a general consensus that protected time should be made available for others working in health and social care to pursue training. This training should be offered to all staff, including front-line staff such as receptionists, who are important in supporting access to services. Lastly, the need for more BME voluntary health and social care/welfare organisations and BME service user groups was identified as being of significant importance, for these organisations do not only provide necessary services and support, they also are ideally positioned to provide other sectors with culturally competent practice models.

Key challenges

A number of key challenges affecting research about the health and social care of BME people in Wales were identified through the study. First was the desirability of user involvement and community engagement in the formulation of research agendas and in the way research is conducted in BME communities, which is a principle now well established in healthcare research (Gunaratnam, 2003). As one commentator appropriately suggested, there is a tension between research outcomes and research process in this respect:

> '... the main challenge is the brokerage of research data between acceptable output parameters required by health and social care methodologies and the completely different set of input values from the BME community. The translation is a non-trivial matter and difficult ...'

Second, linked to this was the view that BME people in Wales have been the subject of considerable research overload and are left disillusioned when findings apparently fail to influence policy and make an immediate difference in their experiences of health and social care. The census group discussions highlighted the challenges raised by the paucity and short-term nature of funding for research with BME groups. These factors confirm findings from a number of research studies (Arai and Harding, 2002). Finding ways of ensuring more effective sharing of knowledge and good practice around particular interventions was also identified as a challenge. The implementation gap between research messages and changes in practice has long been recognised, but this study highlighted the potential for a more strategic and facilitative approach to the support of practitioners. The need for effective consultation mechanisms pitched towards BME households as opposed to community groups was also seen as a research priority.

A third challenge was rooted in the need for an effective mainstreaming of the equality agenda. As one respondent stated, there was a need to 'ensure that research that is considered to have important implications for BME communities in Wales is actively considered, implemented or if not, good reasons are given for not doing so'. This raises wider political issues about the priorities given to BME research by funding bodies in Wales, and the current capacity within research institutions to incorporate diversity and difference in their agendum.

Finally, the specific strategies needed in areas of Wales with low concentrations of BME people and groups were also identified as a challenge. Very little is known about how the particular needs of people from BME backgrounds are met in virtually all those areas in which they represent less than 2% in a locality. This is particularly the case in north and mid-Wales. From the focus groups it became clear that different challenges and research priorities were emerging. For example, in the north, concerns were expressed about the needs of new migrants to the area, in particular migrant workers for the EU accession states, issues of attracting funding to such areas and issues of access to services (Hold *et al*, 2007).

Conclusion: postscript on the way forward

The scoping study represented a strategic Wales-wide approach to a consideration of research priorities for BMEs. The use of a participatory methodology meant that the voice of user groups and key stakeholders across the country shaped this major call for focused research and development activity at a national level. This activity itself provided for a mobilisation of key stakeholders and the political prioritisation of the needs of BMEs. As such it challenges the *ad hoc, laissez faire* approach that has been previously taken to BME research, with the concomitant tendency towards small-scale and frequently duplicated studies. Recommendations from the study proposed the establishment of a research infrastructure aimed at enabling regional and all-Wales research to be reviewed and prioritised and to provide a dedicated research and development context in which to link issues of *ethnicity* and *race* to the key biomedical, clinical and healthcare research underway.

Such an approach to the development of research priorities is not without all the caveats incumbent on user-engagement strategies. This account of BME need must necessarily be partial, given the considerable diversity amongst this population, competing priorities and the orchestration of views which are not always complementary. The scoping study provided only a snapshot of the current articulation of the issues, and began the process of mapping out areas of need from an all-Wales, multisector and

interdisciplinary perspective. It also raised wider questions about the framing of need and responses at nation-specific level, given the way in which minority groups organise and coalesce beyond the boundaries of the nation state, in both the articulation of needs and the ways in which they seek responses for and organise around them.

There is an extensive literature on the needs of BME groups UK wide (*inter alia* Ahmad, 1993; Atkins and Anionwu, 2001; Nazroo, 2003). This body of evidence exists to establish patterns of disadvantage in relation to specific conditions, access issues, racism in service delivery and the needs of particular groups such as Gypsy Travellers and asylum seekers. The experiences of BME peoples in Wales may be typical, in many respects, of BME experience elsewhere, but contextual factors, such as a history of policy neglect, specific social, economic and political factors including legislative and policy divergence under devolution, make pressing the need to find Welsh solutions for Welsh problems. Devolution has produced what some commentators (Adams and Robinson, 2002) have called 'policy laboratories', that provide opportunities for novel experiments that can produce outcomes for policy learning elsewhere. It is to be hoped that the Welsh cross-sector system of collaboration and co-operation that connects academic research with user, community and public in the development of policy and practice will provide such fruitful lessons.

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CONFLICTS OF INTEREST

None.

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