

Better
Health
Briefing

7

**User
participation
in health care
services**

Ossie Stuart

A Race Equality Foundation
Briefing Paper

February 2008

Key messages

- 1 Black and minority ethnic (BME) groups generally have poorer health than the overall population, although the extent of ethnic health inequalities is masked by poor data collection
- 2 Low take-up of services among black and minority ethnic communities is still frequently explained as being due to 'cultural' and social preferences within these communities, despite contrary evidence
- 3 Black and minority ethnic users and carers lack support to use the available information and have little faith in those services that exist
- 4 Users from black and minority ethnic communities want greater diverse provision to be as explicit a goal of health care as it increasingly is of social care
- 5 The NHS workforce should better represent the local communities it serves, especially at senior levels. However, what most black and minority ethnic users really want is better training for all staff
- 6 Despite the importance given by the Department of Health to 'choice' and involvement, user participation still remains an ambition rather than a reality for black and minority ethnic users. However, BME user participation is key to improving the organisation and delivery of health care services.

Introduction

The Local Government and Public Involvement in Health Act became law in 2007. Two measures the Act introduces are the establishment of Local Involvement Networks (LINKs), to replace Patient and Public Involvement Forums, and the abolition of the Commission for Patient and Public Involvement in Health. The Act seeks to clarify and strengthen the existing duty on National Health Service (NHS) bodies to involve and consult patients and the public in the planning and provision of services ([DH, 2007b](#)). The purpose of the Act is to oblige primary care trusts (PCTs) to follow the examples of involvement and consultation developed by local authority-run social care services:

Although many examples of good practice can be found across the NHS, there is inconsistency, and the NHS still has much to learn from the more localised, social care approach to involvement. The trend in social care is to give as much power as possible to service users to design, purchase and manage their own services. This is supported through direct payments and individualised budgets.
([DH, 2006a, p. 10](#))

The Department of Health (DH) considers past attempts by NHS trusts and PCTs to involve users in the planning and commissioning of services to be inadequate. Many PCTs continue to tolerate a lack of meaningful engagement with black and minority ethnic communities when services are being discussed ([House of Commons Health Committee, 2007](#)).

A King's Fund review of 300 PCTs found that a third had still not complied with the Race Relations (Amendment) Act 2000 (King's Fund, 2007). This means that consistent user participation, namely consulting BME users, acting on their views, and involving them in the design of services, remains to be achieved across all PCTs (Begum, 2006). This matters because the only way to reduce the known health inequalities among BME communities is to create meaningful partnerships with these users in order to deliver equitable health care. Social care, on the other hand, has begun to embrace user participation, including BME communities, on a significant scale.

Both the Race Relations (Amendment) Act 2000 and the Disability Equality Duty, part of the Disability Discrimination Act 2005, have been extremely influential in persuading local authorities to begin to consult with and involve BME and disabled users in the design and delivery of social care services. The law is not the only reason why social services have begun to take user participation seriously. There has been a realisation that user participation can deliver real improvements in the quality and efficiency of social care services (Beresford *et al.*, 2005). This is best captured in a document detailing the proposed modernisation of social services published by the Department of Health in late 2007. User participation is at the heart of the plan to deliver change in the way social care is organised, run and implemented (DH, 2007a). The document is replete with terms such as 'independent living', 'involvement', 'empowerment' and 'user participation'. It is no accident that this language echoes that of the 'social model of disability'. This acknowledges the debt owed to disabled people's organisations, which have long argued that greater control and autonomy when using social care services would benefit both users and providers (Oliver, 1993). This debate is long overdue in the health service.

Do BME users receive better treatment when accessing social care services? The answer is probably not. BME users are still the least likely to access social care services (Chamba *et al.*, 1999; Tobin *et al.*, 2006). The Social Exclusion Unit Report on Mental Health and Social Exclusion candidly states that: '*Few people from ethnic minority groups with mental health problems are accessing direct payments despite their potential for facilitating individual and culturally sensitive support*' (Social Exclusion Unit, 2004, p. 43). These reports, and many others like them, paint a picture of continued inequality in social care provision. Yet this should be viewed in the context of change and an increasing number of examples of good practice which seek to ensure that BME users shape and control the services they use (Shaping Our Lives *et al.*, 2007). This is in stark contrast to BME user experiences of health care services. Unlike social care, it is still the case that things 'are done to you' when experiencing health care. In social care there is a more explicit acknowledgment that there has to be a greater partnership of equals between users, carers and professionals to ensure that the inequalities in social care provision are reduced (DH, 2007a). This is a benchmark that health care is expected to follow.

This paper seeks to do three things. First, it sets out to explain the principal barriers that confront BME communities when accessing health services. The second part will then look at what the Department of Health and PCTs are doing to respond to this deficit, and the final part will discuss BME user participation. Why is user participation still an ambition rather than a reality, despite the public duty obligations of PCTs? What could BME user participation look like in a twenty-first century health service?

Resources 1

The King's Fund

www.kingsfund.org.uk/

The King's Fund has a highly successful track record in supporting research, backing community-based health organisations and supporting practical services to improve health and health care for Londoners. Underpinning their work is a commitment to create a health care system that recognises the diversity of London's population and reduces disparities in health between different groups.

Social Care Institute for Excellence

www.scie.org.uk/index.asp

The Social Care Institute for Excellence works to disseminate knowledge-based good practice guidance; to involve service users, carers, practitioners, providers and policy makers in advancing and promoting good practice in social care; and to enhance the skills and professionalism of social care workers through their tailored, targeted and user-friendly resources. It has been at the forefront of work to consult users of health and social care services, especially those users from black and minority ethnic communities.

1 Black and minority ethnic groups: poorer health than the overall population

The evidence that BME communities experience poorer health than the white population is robust ([POST, 2007](#)) and has real implications for local PCTs.

There has been considerable reform of the structure of the NHS in recent years. The role of PCTs has been expanded, and changes have been made in practice-based commissioning, patient involvement, patient choice, competition, and the plurality of providers. Advocates argue that these reforms will make it easier to tailor services to the needs of specific local populations, thus helping to meet the requirements of BME groups. The Department of Health has sponsored the Mosaic programme, which aims to develop good practice in procurement, based on Commission of Racial Equality guidelines ([POST, 2007](#)). However, the lack of baseline data on ethnicity makes it difficult to evaluate the impact of such projects, which in turn makes it hard to identify good practice.

Although anecdotal evidence and qualitative data point to continuing poor experiences and access to health care, quantitative evidence has been hampered by a failure of NHS institutions to collect ethnicity data on patients, at both hospital and primary care level ([King's Fund, 2006](#)). A great deal of activity has clearly been aimed at improving access to health services for BME groups; however, evaluating the outcome of that activity has been difficult due to the absence of this data. Up to a third of hospital data is still not coded, according to the London Health Observatory, and few GP surgeries routinely collect information about their patients ([London Health Observatory, 2008](#)). While the legal and political will to effect change is quite clear and apparent, this is found wanting lower down the health chain. It is assumed that the overarching NHS reforms of increased patient choice, competition and plurality of providers will make it much easier to design and deliver services for minority ethnic groups ([Reid and Phillips, 2004](#)). Without better data it is hard to know whether this is the true outcome.

2 Explaining low take-up of services among black and minority ethnic communities

There has been a low take-up of services among BME communities, especially those from the UK's South Asian populations. With regard to health services, it is well understood that many do not use English as a first language. What is less well recognised is that many — especially parents with disabled children — are isolated and live in the poorest regions and are unlikely to be reached through the usual advertising channels ([Thorlby and Curry, 2006](#)). Furthermore, many BME disabled people with either learning difficulties or a hearing impairment will be extremely hard to include because their communication needs are rarely acknowledged ([BME Health Forum, 2003](#)).

Some service practitioners still assume that this is due to an apparent lack of interest in health and social care services within these communities ([Vernon, 2002](#)). These assumptions are not reflected in the views of users from these communities. For example, in a report for Kensington & Chelsea PCT, rather than lack of interest, most BME organisations reported that users cited a lack of interpreting services; interaction difficulties with GPs, receptionists and hospital staff; difficulties registering with GPs; the length of time before either a GP or a hospital appointment becomes available; and the time allocated to appointments ([Thalassis and Taha, 2006](#)). Research pointed to inappropriate services, lack of information, the desire for proper consultation and advocacy and, finally, cultural insensitivity by practitioners and staff who did not share the same language or background of the users of services, as the reasons for low take-up. BME users, in particular, can lack confidence in service providers and the available service provision. The overall impression is that, rather than a lack of interest from BME communities, low take-up of available services is the result of barriers that prevent people taking advantage of those services.

Lack of support for black and minority ethnic users and carers

3

One of the significant barriers faced by BME communities when attempting to access health and social care services is poor communication (Hussain *et al.*, 2002; Rai-Atkins *et al.*, 2002; Vernon, 2002; Ahmed and Jamshed, 2005; Thalassis and Taha, 2006). An advocacy service to facilitate access and negotiate the available information is a key way to overcome communication and information barriers. However, mainstream advocacy services have had great difficulty adapting their services to meet the needs of a wider, diverse constituency. Mental health advocacy services typify the problems advocacy services face. These include few or no black or bilingual advocates; very few black service users actually accessing the service; relationships with black voluntary mental health projects weak or non-existent; little awareness of the distinctive needs of black service users; and no information provided in languages spoken by minority communities (Rai-Atkins *et al.*, 2002). Users have expressed a deep lack of confidence in mainstream advocacy. They are less likely to take up mainstream advocacy because information about these services is not given to black service users by mainstream agencies; because there is mistrust of both voluntary and statutory agencies; and as a result of language barriers and culturally inappropriate advocacy definitions (Rai-Atkins *et al.*, 2002). Those advocacy services set up to support BME communities are often precariously funded and pressurised black projects, having little time for community development (Thalassis and Taha, 2006).

What users look for from advocacy is support to overcome the barriers they face. Solutions suggested to improve advocacy go beyond mental health services. They include:

- advocacy that challenges assumptions and prejudices held by practitioners;
- advocacy that promotes the integration of complementary health approaches, and facilitates access to culturally appropriate services;
- advocacy that empowers black service users and their carers to identify their own needs and culturally appropriate ways to meet them;
- independent and accessible black-led advocacy services for black service users;
- advocates who reflect users' cultural background, language and gender (Rai-Atkins *et al.*, 2002).

The need for greater diverse provision to be an explicit goal of health

4

There is a growing body of research which has sought opinions of what users want from health and social care, and what would make a difference to them (Wallcraft *et al.*, 2003; Carr, 2004; Beresford *et al.*, 2005; Butt, 2005; DH, 2006b; Beresford and Shaping Our Lives, 2007). From this body of work users, including those from BME communities, are in agreement about what they want from health and social care services:

Resources 2

Joseph Rowntree Foundation

www.jrf.org.uk/about-us/

The Joseph Rowntree Foundation is one of the largest social policy research and development charities in the UK. For over 100 years it has been searching out the causes of social problems, investigating solutions and seeking to influence those who can make changes. It has specific research programmes on the views and experience of black and minority ethnic users of health and social care.

MIND

www.mind.org.uk/index.htm

Mind is the leading mental health charity in England and Wales. It works to create a better life for everyone with experience of mental distress. It holds valuable information on black and minority ethnic groups.

Race for Health

www.raceforhealth.org/

The Race for Health programme enables PCTs to make the health service in their areas significantly fairer for black and minority ethnic communities. The programme supports a network of fifteen PCTs around the country, working in partnership with local black and minority ethnic communities to improve health, modernise services, increase choice and create greater diversity within the NHS workforce. More PCTs, some in more rural areas, are expected to join in 2008.

- to be consulted about and involved in the design of services for them;
- services that are holistic: this means that all aspects of a service user's life should be considered;
- services that enhance independence, choice and control;
- the expansion, rather than restriction, of direct payments;
- increasing diversity as an explicit goal of social care.

To bring this about, the following needs to be put into place:

- more and targeted information;
- senior management commitment;
- secure finance;
- better staff training;
- consultation and involvement ([Stuart, 2007](#)).

This list is remarkably similar to the 'wish list' created by BME user organisations when asked what would make a difference to the problem of accessing GP and hospital services. They listed the following:

- There is a need to raise awareness of access issues and training provision among health professionals, especially GPs, practice managers and receptionists.
- While patient education and developing the BME communities' understanding of health provision is important and should be catered for, the focus must remain on the need to examine all aspects of access to ensure that needs are met.
- Collection of ethnicity data at primary and secondary care levels is essential to understanding inequalities in access to health services ([Thalassis and Taha, 2006](#)).

5 The NHS workforce should better represent the local communities it serves

The request that the NHS workforce should better represent the communities it serves is repeatedly made by users in research ([Hussain *et al.*, 2002](#); [Vernon, 2002](#); [Stuart, 2006](#)). With the likelihood that BME employees are disempowered junior front-line staff, better representation among senior staff is perhaps the more important request to make. Yet, changes in European Union membership have meant that a growing number of social care employees are now from Eastern Europe ([BBC, 2007](#)). This has implications for users of services from other minority ethnic communities. BME users are more likely to meet workers whose first language is not English and who may not be confident about working with people whose backgrounds are very different from their own. This has been recognised by BME users who, in recent research, ask not for compatible workers, but for effective training and support for all employees ([Butt, 2005](#); [Stuart, 2007](#)).

Innovative projects that place users at the heart of the service can only succeed if staff are motivated and are as involved as the users in the service design. Rather than the workers being the 'problem' when creating 'person-centered' or user-led services, they are key allies who will gain as much from the transformation of health and social care services as the users ([Standards We Expect, 2008](#)).

6 User participation: an ambition rather than a reality for black and minority ethnic users

The purpose of the decision by the Government to establish LINKs is to exploit the experience of local authorities' social care services when involving users in service delivery. Some PCTs have already begun to use this model to stimulate BME voluntary sector participation in service delivery. Some examples of good practice are given below.

The BME Health Forum is a formal bridging structure: a collaborative partnership network between statutory, voluntary and BME community organisations. It aims to improve health and reduce inequalities for BME communities in the Royal Borough of Kensington & Chelsea and the City of Westminster (KCW) ([BME Health Forum, 2008](#)). It achieves this by developing knowledge and an understanding of the health concerns of the diverse range of BME communities in KCW. The Forum works across the two boroughs in response to the needs and location of BME communities, irrespective of borough boundaries, while at the same time being mindful of, and responsive to, the different priorities and cultures of the statutory authorities. The Forum has quarterly members' and participants' meetings for discussion and information exchange.

Women's Health and Family Services is a multi-ethnic health advocacy, support and advice organisation which works closely with Tower Hamlets PCT ([Women's Health and Family Services, 2008](#)). It is mainly an advocacy and translation service for Bengali, Cantonese, Somali and Vietnamese women. The advocates are employed staff who work directly with GPs, midwives and health visitors, and facilitate clients to be able to speak for themselves. These advocates have helped to identify gaps in provision to BME communities in Tower Hamlets.

Mary Seacole House in Liverpool is a local voluntary organisation which runs a multicultural mental health day centre primarily for people from BME communities, who are living with mental health issues and who also encounter racism or discrimination in their day-to-day living. Mary Seacole House provides a day care service and an outreach service. It also hosts an advocacy project which represents people, primarily from BME communities, who are living with mental health problems. Its staff have developed significant specialist knowledge of the needs of these communities across Liverpool, and have been able to represent these to the City Council's social services department and Liverpool PCT in order to influence service provision. Both the social services department and the PCT fund some of the core costs ([Mary Seacole House, 2008](#)).

Both the Westminster and Liverpool schemes are part of Race for Health, initiated by the Department of Health (see Resources).

What the schemes described above have in common is that each successfully acts as an advocate for their target communities, although in different ways. They have each indicated how PCTs can design better services for some BME users. It is also clear from these schemes that there is not just one way to foster user participation. However, they also share a view which assumes that the lack of user participation arises because the BME community does not engage with what are essentially 'valuable services'. Services for cancer, mental health, and so on, might be changed a little here and there to ensure improved access for BME communities, but they remain fundamentally unchanged. The question that arises is, will improved engagement with the BME communities correct the 'problem' of poor take-up from these communities?

Conclusion

The National Health Service is vast. It offers a service on such a scale that, rather than being a single entity, it comprises many services run under a single rubric. The lesson that social care has just begun to learn is that the reason for unequal access is not that we live now in a new, diverse Britain. We have always lived in a diverse Britain (rich or poor, old or young, northern or southern). Rather, the problem of unequal access arises because the NHS persists in creating barriers. The question that has to be asked is, who is the NHS actually for? Consistent and meaningful change will only come about when the NHS accepts that it is the problem. Clinicians, specialists, consultants and professionals need to learn how to participate with users, rather than the other way round. Paternalism is at the heart of the way in which the NHS does business. This damages all users: it is just that BME users can be the most damaged of all.

References

- Ahmed, T. and Jamshed, H. (2005) 'Reaching out: how to tackle diabetes in the Asian population', *Primary Care Report*, 7, 8, pp. 14–15.
- BBC (2007) *What Jobs are EU Migrants Doing?*, http://news.bbc.co.uk/1/hi/uk_politics/5273976.stm (last accessed December 2007).
- Begum, N. (2006) *Doing It for Themselves: Participation and black and minority ethnic service users*, London: Social Care Institute for Excellence/Race Equality Unit.
- Beresford, P., Shamash, M., Forrest, V., Turner, M. and Branfield, F. (2005) *Developing Social Care: Service users' vision for adult support*, London: Social Care Institute for Excellence.
- Beresford, P. and Shaping Our Lives (2007) *The Changing Roles and Tasks of Social Work from Service Users' Perspectives: A literature informed discussion paper*, London: Shaping Our Lives.
- BME Health Forum (2003) *Report On User & Public Involvement Initiatives May–December 2002*, www.westminster-pct.nhs.uk/pdfs/bme_report_user_involvement_initiatives_may03.pdf (last accessed January 2008).
- BME Health Forum (2008) www.westminster-pct.nhs.uk/diversity/bmehealthforum.htm (last accessed January 2008).
- Butt, J. (2005) *Are We There Yet?: Identifying the characteristics of social care organisations that successfully promote diversity*, Race Equality Discussion Paper, London: Social Care Institute for Excellence.
- Carr, S. (2004) *Has Service User Participation Made a Difference to Social Care Services?*, SCIE Position Paper 3, London: Social Care Institute for Excellence.
- Chamba, R., Ahmad, W., Hirst, M., Lawton, D. and Beresford, B. (1999) *On the Edge: Minority ethnic families caring for a severely disabled child*, Bristol/York: The Policy Press/Joseph Rowntree Foundation.
- Department of Health (DH) (2006a) *A Stronger Local Voice: A framework for creating a stronger local voice in the development of health and social care services*, London: Department of Health.
- Department of Health (DH) (2006b) *Dignity in Care Public Survey October 2006 – Report of the survey*, London: Department of Health.
- Department of Health (DH) (2007a) *Putting People First: A shared vision and commitment to the transformation of adult social care*, London: Department of Health.
- Department of Health (DH) (2007b) *The Local Government and Public Involvement in Health Act 2007*, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_076445 (last accessed January 2008).
- House of Commons Health Committee (2007) *Patient and Public Involvement in the NHS: Third Report of Session 2006–07*, London: The Stationery Office, www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/278i.pdf (last accessed January 2008).
- Hussain, Y., Atkin, K. and Ahmad, W. (2002) *South Asian Disabled Young People and Their Families*, Bristol/York, The Policy Press/Joseph Rowntree Foundation.
- King's Fund (2006) *Access to Health Care and Minority Ethnic Groups*, King's Fund Briefing, London: King's Fund.
- King's Fund (2007) *Lack of Data Hampers PCTs' Efforts to Ensure Race Equality in Local Health Services*, King's Fund Report, www.kingsfund.org.uk/media/lack_of_data.html (last accessed January 2008).
- London Health Observatory (2008) *Ethnic Health Intelligence Programme*, www.lho.org.uk/HEALTH_INEQUALITIES/EHIP/EthnicHealthIntelligence.aspx (last accessed January 2008).
- Mary Seacole House (2008) www.maryseacolehouse.co.uk/ (last accessed January 2008).
- Oliver, M. (1993) *The Politics of Disablement: Critical texts in social work and the welfare state*, London: Macmillan.
- Parliamentary Office of Science and Technology (POST) (2007) *Ethnicity and Health, Briefing No. 276*, London: Parliamentary Office of Science and Technology.
- Rai-Atkins, A., Ali Jama, A., Wright, N. et al. (2002) *Best Practice in Mental Health: Advocacy for African, Caribbean and South Asian communities*, Bristol/York: The Policy Press/Joseph Rowntree Foundation.
- Reid, J. and Phillips, T. (2004) *The Best Intentions? Race, equity and delivering today's NHS*, London: Fabian Society.
- Shaping Our Lives, NCIL and University of Leeds Centre for Disability Studies (2007) 'Developing social care: service users driving culture change', *People Management Knowledge Review*, 17, Social Care Institute for Excellence.
- Social Exclusion Unit (2004) *Mental Health and Social Exclusion*, Report, London: Office of the Deputy Prime Minister.
- Standards We Expect (2008) *Participatory Approaches to Developing Person-centred Support*, Joseph Rowntree Foundation (forthcoming), www.standardsweexpect.org/ (last accessed January 2008).
- Stuart, O. (2006) *Will Community Based Support Services Make Direct Payments a Viable Option for Black and Minority Ethnic Service Users and Carers?*, SCIE Discussion Paper, London: Social Care Institute for Excellence.
- Stuart, O. (2007) *What Service Users Want From (Adult Social Care) Services and What Makes a Difference?*, SCIE Discussion Paper, London: Social Care Institute for Excellence.
- Thalassis, N. and Taha, A. (2006) *Minding the Gaps: A report by the BME Health Forum*, www.westminster-pct.nhs.uk/pdfs/MindingTheGaps.pdf (last accessed January 2008).
- Thorlby, R. and Curry, N. (2006) *Valuing Equality Paper for National Race for Health Conference 22–23 November*, London: King's Fund.
- Tobin, R., Vick., R. et al. (2006) *An Evaluation of the Impact of the Social Care Modernisation Programme on the Implementation of Direct Payments*, London: Health and Social Care Advisory Service.
- Vernon, A. (2002) *User-defined Outcomes of Community Care for Asian Disabled People*, Bristol/York: The Policy Press/Joseph Rowntree Foundation.
- Wallcraft, J., Read, J. and Sweeney, A. (2003) *On Our Own Terms: Users and survivors of mental health services working together for support and change*, London: Sainsbury Centre for Mental Health.
- Women's Health and Family Services (2008) www.whfs.org.uk/index.html (last accessed January 2008).

Ossie Stuart is a full-time diversity consultant specialising in ethnicity and disability. As a social policy researcher at the University of York and the University of Surrey, Roehampton, he has published influential works on race and disability. He is a member of the JRF Independent Living Committee, and in 2006 wrote an important report for the Social Care Institute for Excellence on BME disabled people's access to direct payment services.

Readers

Patricia Chambers
Wallen Matthie
Roger Steele

We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk

Copyright © Race Equality Foundation
February 2008
Copy-edited by Fiona Harris 01908 560023
Graphic design by Artichoke 020 7252 7680
Printed by Crowes 01603 403349
ISBN 978 1 873912 12 9

Race Equality Foundation
Unit 35
Kings Exchange
Tileryard Road
London N7 9AH
T: 020 7619 6220 F: 020 7619 6230
www.raceequalityfoundation.org.uk

**Race
Equality
Foundation**

