



LINK Report

**Exploring health and social care
needs of people in black and
minority ethnic communities in
North Tyneside**

**Report produced for North Tyneside Local
Involvement Network (LINK) by the Health
and Race Equality Forum (HAREF)**

health & race 
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Summary of findings

There are **information gaps** in relation to:

- The range of local health and social care services and how to access and use them effectively. Lack of information can lead to under-use of services, for example screening programmes.
- What to do to take small steps towards change, for example in preparing and cooking food, to live as healthy a life as possible.

Community and religious leaders can be a **health promotion resource**, reinforcing messages about ways to stay healthy and how to avoid developing or worsening long term conditions.

There is a need to extend **exercise opportunities for people living with long term conditions** such as diabetes and coronary heart disease. Participants highlighted the social, emotional and physical benefits of exercise and other health promotion interventions.

Mental health is an area of significant need. The difficulty of recognising and 'naming' mental ill-health was highlighted by participants across communities. There are particular issues for people who arrive in the UK seeking asylum, many of whom have experienced trauma.

Age related issues such as disability, caring responsibilities, and difficulties when there is no or little family support at hand, were identified by participants from South Asian communities in which there are ageing generations.

There is awareness of the need to open up discussion around sensitive areas of health promotion and prevention of ill-health, such as **use of alcohol and other substances, sexual health** and **domestic violence**.

In relation to **interpreter support**, there are issues of inconsistent use of interpreters by health and social care professionals, inconsistent quality of interpreter support, and problematic use of young people as informal interpreters.

Participants from black and minority ethnic communities expressed enthusiasm for **making things happen through partnership** with commissioners: "We can sort a lot of problems together, listening to each other and helping each other."

Next steps

North Tyneside Health and Wellbeing Board working in partnership with LINK (local HealthWatch from April 2012) and other organisations should:

- Develop working links with people in North Tyneside minority ethnic communities.
- Work with these communities to provide meaningful and useful information on how to access local health and social care services.
- Work with these communities to promote small steps towards leading as healthy lives as possible.
- Continue to develop the local North Tyneside Joint Strategic Needs Assessment to ensure it is culturally responsive to the needs of minority as well as majority ethnic communities.
- Develop criteria for commissioning high quality professional interpreter support.
- Support North Tyneside people from diverse black and minority ethnic backgrounds to use the various existing local mechanisms to 'have a say', for example LINK (local HealthWatch from April 2012), Older People's Forum and Disability Forum.
- Support North Tyneside people from diverse black and minority ethnic backgrounds to get together to produce collective community intelligence to inform commissioning and development of services.

Background

The Health and Race Equality Forum (HAREF) was asked by North Tyneside Local Involvement Network (LINK) to explore health and social care needs of people in black and minority ethnic communities in the local authority area.

The term 'black and minority ethnic communities' represents a wide range of identities, nationalities, cultural and religious practices, as well as the shared experience of being in a minority in relation to a majority white population (Afiya Trust 2010). It is important to acknowledge diversity within black and minority ethnic communities in terms of people's age, sexuality, gender, faith, caring responsibility, socio-economic status, sensory, physical and learning ability (not an exhaustive list).

Some people may experience double discrimination, for example older people with minority ethnic status (Cooper et al 2000), and people from a minority ethnic community who are lesbian, gay and bisexual (Hunt and Minsky 2006).

Some experience triple disadvantage, for example young people from minority ethnic communities with learning disability (Warwickshire Race Equality Partnership 2009).

There is an increasingly diverse UK population in terms of ethnicity and first language (Healthcare Commission 2009, Rasul and Cross 2006). North East England mirrors this, with established South Asian communities and people who have arrived more recently to work, study, join families or seek asylum (Rodger and Chappel 2008).

North Tyneside Council (2008) acknowledges a lack of reliable data on the ethnicity of people currently living in the borough. A joint commissioning strategy document (North Tyneside Council and NHS North of Tyne 2010) estimates that 3.9% of the population (reported as 195,000, with 120,400 people of working age, in a North Tyneside profile prepared by Government Office for the North East in 2007) are from black and minority ethnic communities, whereas a report profiling minority ethnic communities, commissioned by North Tyneside council, calculates that they make up 5.6% of the population, based on 2007 mid-year population estimates (Experian 2010). Analysis of the 2011 Census data will

give a more accurate picture of the current population in relation to ethnic diversity.

The North East of England is one of the three UK regions where small area analysis of 2001 Census data showed health inequalities at birth at their widest (Rasulo et al 2007).

Ethnicity is a factor in health inequalities (Rao et al 2010, Wilkinson and Pickett 2010) and the health of people in UK Black and minority ethnic communities is poorer than that of the majority white population by almost all health measures (Shukla 2010, Long et al 2009, Parliamentary Office of Science and Technology 2007).

This translates into limiting long-term illness and lower life expectancy for people in some communities, for example those of Pakistani and Bangladeshi origin (Equality and Human Rights Commission 2010, El Ansari et al 2009, Ali et al 2008, Improvement and Development Agency 2010).

Some people who arrive in the UK seeking asylum need tailored support for complex physical and mental health difficulties linked to trauma in their country of origin and during their journey to a place of safety (UK Border Agency 2009, Refugee Council 2006).

There is significant evidence of the link between health inequalities and ethnicity (Acheson 1998), reflected in strategies over the last twenty years (National Association of Health Authorities 1988). Crowley (1996) cites the Chief Medical Officer's report on the state of public health in 1991 (Department of Health 1992):

The NHS must address the particular needs of black and minority ethnic minorities living in this country and take positive steps to eliminate discrimination.

This task remains challenging (Carlisle 2010, Social Exclusion Task Force 2010). However, the current point of transition for the NHS (Department of Health 2010) provides an opportunity for commissioners in North Tyneside's local authority and two GP consortia to think innovatively and creatively about ways of getting to know and understand the health and social care needs of people in black and minority ethnic communities (Sharma 2010, Government Equalities Office 2009 and 2010, Bentley 2008, Hally 2008).

HAREF workers facilitated group and individual interviews with people from a range of minority ethnic communities who live in the North Tyneside area:

Small group interviews with Cantonese-speaking women and men, and Bengali-speaking women, and individual interviews with a member of the Farsi-speaking group that meets regularly (including people from Iran and Afghanistan), a member of the Bengali community, and a member of the regional African Women's Support Network.

Further individual and small group interviews involved practitioners, managers and commissioners working, respectively, with North Tyneside Council, Newcastle and North Tyneside Community Health, a North Tyneside GP commissioning consortium, and a voluntary sector organisation.

Everyone was asked to talk, from their perspective, about who lives in North Tyneside in terms of people from black and minority ethnic communities, the health and social care needs they might have, and the potential for connecting with people across communities to inform the commissioning process.

The number of people with whom HAREF workers met was smaller than planned because of severe weather conditions towards the end of 2010. Several group interviews arranged for the end of November and beginning of December could not take place, and the numbers of people taking part in the group interviews that went ahead were smaller than expected. This is a limitation, balanced by the amount and quality of information shared by participants.

The ages of the people from black and minority ethnic communities who took part from both established and emerging communities ranged from 30s to early 70s. Participants described their cultural backgrounds as Bangladeshi, Chinese, Iraqi, African (mentioning the country would risk identifying the interviewee) and their first languages are Farsi, Cantonese, Bengali and French. HAREF workers facilitated group discussions with bilingual colleagues as appropriate.

Group discussions took place in venues familiar to participants and each group was given a fruit basket or a sandwich lunch as a

gesture of thanks for their time. People did not know in advance that they would receive this.

Findings

- Quotes from people who took part in the research are in speech marks. To protect confidentiality, they are identified as being from either a person from a North Tyneside minority ethnic community or a practitioner, manager or commissioner.
- At the end of each section there is reference to UK literature review (research articles, strategic reports etc).

1. Changing population

There is an expanding range of minority ethnic communities in the North Tyneside area. One participant estimated that Farsi-speakers make up the largest single community, with another suggesting that the number of people whose first language is Farsi is approximately 400. One interviewee shared a perception that the community of people arriving from African countries is the fastest growing. The same person suggested that approximately 40 first languages are spoken in North Tyneside.

“We used to be able to count ourselves in the 1980s and then more people started arriving, and there is quite a large (Bangladeshi) community spread across North Tyneside now”.

“North Tyneside is a lot more diverse than we think. We don’t take on board sexuality and ethnicity. The current Joint Strategic Needs Assessment doesn’t refer to people from black and minority ethnic communities.” (Practitioner, manager, commissioner)

People from South Asian backgrounds have been part of the North Tyneside population for many years and some families expand through the addition of husbands, wives and other relatives from places of origin.

Some people from minority ethnic backgrounds have arrived more recently for work opportunities, for example, people from the Philippines and white minority ethnic workers from Eastern Europe.

Some have sought asylum in the UK, for example from Iran, Iraq, Afghanistan and African communities (participants referred to knowing people who have arrived from Cameroon, Zimbabwe, the Democratic Republic of Congo, Angola and Rwanda). At present, according to one participant, there are fewer than 100 people seeking asylum living in North Tyneside, with 3000 living across the North East of England. Some people who have arrived seeking asylum over the last ten years have stayed on in North Tyneside, having developed friendships and relationships and found employment.

The two quotes below from people in North Tyneside's ethnic minority communities are, respectively, an expression of anxiety in response to lack of knowledge about different cultural and spiritual backgrounds, and a positive response to increased opportunities through diversity. They illustrate the complexity and the potential of the task of developing social cohesion and inclusion.

“I feel more scared as I don't have much knowledge about different religions and cultures.”

“There are a lot of people from different backgrounds. I see them every day walking around. Times have changed and it's good that there are so many different types of people. Before I felt there was more racism, and now there are so many types of shops and different foods.”

2. Information gaps

Information gap: How do services work?

Several participants from established minority ethnic communities have a good grasp of how the NHS works and gave positive feedback about their primary care service.

“Without a shadow of a doubt, doctors here are the best in the world. They are very thorough and in general we're very happy with the doctor's attention and follow-up of things”.

“The family doctor is very good. I feel that I can ask questions.”

However, interviewees highlighted people’s difficulties in finding out about health and social care services, how they work, and how to access and use them effectively. The following quotes are from people in minority ethnic communities.

“People who arrive here are coming from a different world. Everything is unfamiliar and they cannot communicate.”

“People are not aware of what’s there and don’t know about the importance of registering with a GP.”

“I remember I was walking around to see if I could see a clinic.” (Person who arrived seeking asylum)

A practitioner, manager, commissioner made a similar point.

“Part and parcel of building trust is getting to know systems and how things work here. The ways in which systems are set up can make it difficult for some to use them.”

Information gaps can result in under-use of services and poorer outcomes for people in relation to their health and social care needs. For example, out of 3517 people in receipt of an adult social care costed service in North Tyneside, 17 adults (over 18 years) are recorded as being from a minority ethnic community, with three people’s ethnicity unrecorded (North Tyneside Council and NHS North of Tyne 2010). This would appear to be a disproportionately low number.

“If you don’t know anything, you can’t get anything.”
(Person from a North Tyneside minority ethnic community)

“There is a general lack of information about what social care is, what is available and who to contact about eligibility etc. We need to be proactive and get out there and find out what people in minority ethnic communities need to know. Small numbers of people are in receipt of social care proportionate to the size of their communities in North Tyneside. It’s important to get information about

personalisation and dementia, for example, out to communities and not just translate information.”
(Practitioner, manager, commissioner)

When there are information gaps, people are left poorly equipped to meet their responsibilities in relation to services.

“Some people don’t understand the concept of making an appointment with the doctor and some don’t understand the importance of punctuality in relation to health and social care consultations.” (Person from a North Tyneside minority ethnic community)

UK literature review: Many people in minority ethnic communities experience difficulty in finding out about how health and social care services work and how to use them effectively (Ellins and McIver 2009, Lakhani M 2008, Hawthorne 2007, Scottish Executive 2007, Kensington, Chelsea and Westminster BME Health Forum 2002, Manthorpe et al undated).

Information gap: How to take small steps towards change, to stay as healthy as possible?

Several participants identified information gaps in relation to what to do to take small steps towards change, for example in preparing and cooking food. Their understanding of the importance of a healthier diet was counterbalanced by the complexity of making changes to the food they usually eat, which is invested with more than calorific value.

“People want to eat healthier, but they value the food that belongs to their cultural background, because it is a reminder of who you are.”

Information gap: Cancers and screening

Several people across more than one ethnic minority community talked about information gaps in relation to symptoms and treatment programmes for different cancers, particularly bowel and breast cancer.

“I feel very worried because I don’t know what to expect (in relation to a recent diagnosis).”

Interviews with some people from minority ethnic communities highlighted information gaps that represent a barrier to health, for example a lack of understanding of the purpose of screening.

“People are not open to thinking “I need to do that”, for example having an HIV test.”

“People will not come forward. It’s easier to ignore the letter.”

Some prevention areas are more sensitive than others and require discussion with people in a range of communities about the best ways of sharing information. For example, there was reference to stigma and a sense of shame in relation to intimate parts of the body and the whole area of sexual health. One woman talked about missing several appointments for a cervical smear test because she did not know what was involved.

“Nobody told me why I should have it and when they explained I just said I didn’t need it because I was too embarrassed to go.”

UK literature review: Research identifies limited awareness of screening programmes within black and minority ethnic communities (Johnson 2010). This is of concern in the context, for example, of rising breast cancer incidence, poor breast cancer awareness and low screening uptake among South Asian women (Jain 2010).

Filling the gaps for communities

The North Tyneside Community Development Worker (CDW) team, introduced through the national Delivering Race Equality (DRE) in Mental Health initiative, was referred to as an important resource for people in minority ethnic communities.

“There have been comments back from GPs and Health Visitors that the CDW support is very beneficial for people in minority ethnic communities. They do a lot of awareness-raising among professionals as well.”
(Practitioner, manager, commissioner)

Participants referred to the CDW team’s success in increasing people’s knowledge of, and trust in, local health and social care

services. For example, the team offers an introduction to the NHS in people's first language. They are also skilled in increasing people's confidence and capacity to access the services they need.

"They encourage people by saying: 'This isn't a problem. These services are there for you'." (Practitioner, manager, commissioner)

The importance of getting information about health and social care services to minority ethnic communities was highlighted, with further examples of resources.

"Events for people in Chinese communities living across North of Tyne are usually held in Newcastle (for example at the Chinese Healthy Living Centre), and they're a very good way of getting information to people." (Practitioner, manager, commissioner)

Filling the gaps for professionals

The CDW team has provided race equality awareness sessions for health and social care professionals, often in partnership, for example a joint quarterly training event for social workers on safeguarding vulnerable adults, facilitated with the Community Matron with responsibility for refugees and people seeking asylum, local authority social care practitioners and the Newcastle Interpreting Service.

The CDW team's training sessions with primary care teams have had positive impact, for example in building professionals' confidence to work with people across communities.

"It has helped people in the team, including GPs and receptionists, to understand that everyone from a particular community is not all the same. I think it's helped them to be less fearful of making a mistake. Service providers assume a lot and don't ask. One person said 'What do I say? How do I speak to them?' and we said 'Speak to them as you would anyone else. If you're not sure, just ask.' "

They have also filled a primary care team information gap by explaining some of the practical issues that prevent people using services. For example, in response to the comment: 'We have sent

so many letters about appointments and the family doesn't turn up', they have opened up discussion about different ways of communicating with people whose first language is other than English.

3. Living as healthy a life as possible with long term conditions

Diabetes and coronary heart disease were mentioned by participants from South Asian communities, who illustrated the social and emotional, as well as physical, aspects of exercise and other health promotion interventions. The need for discussion about ways of extending opportunities for exercise and social contact, including for people who have difficulty getting out of the house, was emphasised.

“When I go to use exercise facilities at the gym, the women talk about high and low blood pressures and aches and pains. But the women go because it is an opportunity to socialise and get out of the house. It makes a change from the daily routine. Once I was really ill but I still went swimming because I can use the steam room and felt better going.” (Older person from a South Asian community)

“I have heart problems and I can't get out and about by myself. I feel bad that my health is getting worse and I can't do much about it. I suffer angina and get palpitations and panic attacks. I would like to exercise because it would make me happier.” (Older person from a South Asian community)

There was reference to the tension, for people who are Muslim and living with long term conditions, between religious teaching and health professionals' advice.

“If the doctor advises you not to fast (during Ramadhan), you will not listen to the doctor. Sometimes you are following your faith, not your doctor, for example if they say 'Don't fly to go on pilgrimage because of your heart' ”.

Interviewees identified the potential of community and religious leaders as a resource for enhancing messages about ways to stay healthy and avoid developing or worsening long term conditions.

“Scholars and community leaders try to encourage people not to smoke, by explaining that smoking is damaging.”

UK literature review: People in Pakistani and Bangladeshi communities have rates of diabetes five times higher than the general population, and South Asian people (not including the Chinese community) have twice the prevalence of heart disease (Rasul and Cross 2006).

Diabetes and cardiovascular disease are identified as the most common conditions contributing to premature death and ill health in North Tyneside (North Tyneside Council and NHS North of Tyne 2010). 44% of Bangladeshi men smoke compared with 27% of the general population, and people in the South Asian community as a whole are 50% more likely to die prematurely from coronary heart disease than the majority white population (Bower et al undated: 2009 or 2010 based on cited references).

An NHS commissioned survey of the health of minority ethnic communities showed Chinese adults exercising at relatively low levels, though smoking and drinking alcohol less than the rest of the population (referenced in Mind 2010).

Research suggests that while there is persistent inequality in access to sport and exercise opportunities for people in minority ethnic communities (Long et al 2009), there is great scope for interventions to prevent the development and worsening of long term conditions (Local Government Association 2010).

4. Mental health

Mental health was identified as an area of significant need. The following quotes from people in minority ethnic communities refer to factors that can affect the mental wellbeing of older and younger people. The difficulty of recognising and naming mental ill-health was highlighted by participants across communities.

“Depression can be because of isolation. It’s nice to meet people. If you stay at home you don’t get exercise and you get ill quickly. If you move, you feel re-energised. For young people I think work-related stress and financial stress lead to problems in mental health. Also family issues affect young people. Young people talk about drugs and smoking.”

“It’s like a taboo in our culture. If a person has mental health problems, he or she doesn’t want to speak about it with other people and tries to hide it. They don’t want to go to a health professional, so when they do go it’s often a crisis point.”

“People have the idea that it (depression) will go away itself. Not sleeping is not seen as part of it.”

There are particular issues for people who arrive in the UK seeking asylum many of whom have experienced trauma.

“Mental health is the biggest area of need for most of the black and minority ethnic communities in North Tyneside, in particular the Iranian community as many have had to flee violence and have been victims of torture. They fear for the safety of family members who remain in Iran, and that also has an effect on their mental health. Wallsend Mental Health Team is a fantastic resource.” (Practitioner, manager, commissioner)

The concept of possession in some communities was mentioned in relation to the importance of acknowledging and working with, rather than against, people’s religious beliefs when they experience mental ill-health.

UK literature review: Mental health is highlighted as an area of particular concern in relation to people in minority ethnic communities (Sashidharan 2003), with research suggesting that mental health services across statutory and voluntary sectors tend to fail them (Race Equality Foundation 2008, Connelly et al 2006).

The risk of practitioners making assumptions and stereotyping is highlighted (Joule and Levenson 2008, Moriarty 2008, Lam 2002). For example, a study exploring primary care professionals’ ideas

about depression in older people found that participants hesitated to mention depression in consultations with older Asian and Caribbean people because they thought they might not want to think about themselves as 'depressed' (Murray et al 2006).

An evaluation of the North East Focussed Implementations Site of the national initiative: Delivering Race Equality (DRE) in Mental Health recommends that mental health professionals develop greater understanding of the different mental health and wellbeing beliefs of diverse minority ethnic communities (Remnant 2009).

A North East conference identified that Chinese people are not using mental health services because of information gaps (Newcastle Chinese Healthy Living Centre and HealthWORKS Newcastle 2007). Research into the mental health needs and experiences of people in the Chinese community in Barnet, London, similarly highlighted information gaps and consequent under-use of services (Mind 2010).

The same finding emerged from an exploration of mental health in Newcastle Asian communities in the early 1990s (Ahmed et al 1991), a mid-1990s mapping exercise of mental health service provision for people in minority ethnic communities in Newcastle and North Tyneside (Crowley 1996), and a Mental Health Day in Newcastle at the beginning of the millennium (Black Mental Health Forum 2002).

5. Issues for older people

Disability that can come with age, caring responsibilities, and difficulties when there is no or little family support at hand were identified as health and social care issues by participants from established Chinese and Bangladeshi communities in which there are ageing generations. Several identified support from family members who can easily access information and resources, as a protective factor.

“Nowadays older people in the Bangladeshi community with educated adult daughters and sons have access to services through them. They grew up in this country and they know where to go to sort things out”.

Not everyone has this source of support however.

“I am a carer for my husband and there are so many issues, but I feel there is not enough support for me. There is nobody to encourage my husband to exercise or socialise. I feel down and it’s affecting my health.”

Older participants identified the importance of recognition of their communication support needs.

“I don’t like it when I go to hospital sometime. I get treated like I’m dumb. Instead of talking slowly, they raise their voice as if I’m deaf. It’s very patronising. I wish I could say something back. I feel so frustrated. Usually people are nice though, it’s just sometimes”.

UK literature review: There is an increasing number of older people from black and minority ethnic communities living in the UK. Some of them become physically or mentally unwell at an earlier age than the general population because of factors linked to poverty and disadvantage, linked in turn to their ethnicity (Falkingham et al 2010, Connelly 2006).

In relation to people who have arrived in the UK seeking asylum, their experiences in their country of origin, during their journey, and after arrival, affect their physical and emotional wellbeing (Connelly 2006).

The impact of lack of family support is highlighted (Cattan and Giuntoli 2010). Research suggests that carers in minority ethnic communities are under-represented in involvement initiatives and user organisations (Gregory 2010).

6. Sensitive areas of health promotion and prevention of ill-health

Participants across communities referred to sensitive areas of health promotion and prevention of ill-health such as use of alcohol and other substances, highlighting the importance of opening up discussion with people from minority ethnic backgrounds.

“Alcohol tends not to be a big issue for people in Muslim communities because of our religion. Some do drink, though usually not to excess, but young people mix with other young people and do drink.”

“Drugs will become an issue, probably for single young men who have difficulty getting employment. That and alcohol can be a form of escape. There’s stigma but there’s real need for discussion now. Prevention is better than treatment.”

“Some older people pipe-smoke (opiates) and sometimes this is linked to feeling depressed and wanting to feel better, even though that doesn’t make sense.”

There was appreciation of the input of schools to equipping young people with the information they need in areas such as sexual health, which people in older generations might find difficult because of lack of knowledge and embarrassment.

“Younger people are quite well equipped because of the information they get in school (about sexual health). Older people need more information.” (Person from a North Tyneside minority ethnic community)

The importance of discussing the needs of women from black and minority ethnic communities in relation to the spectrum of domestic violence, which includes forced marriage and female genital mutilation, was mentioned by a practitioner, manager, commissioner.

UK literature review: The importance of discussing the needs of people of all ages in black and minority ethnic communities in relation to the public health areas above has been highlighted (Women’s National Commission 2010, National Institute for Health and Clinical Excellence 2009, Sundari and Gill 2009, Dustin and Phillips 2008, Medical Foundation for AIDS and Sexual Health 2008, Department of Health 2007, Gangoli et al 2005, Parmar et al 2005). There is evidence of information gaps and under-use of services in relation to sexual health (Samangaya 2007).

7. Interpreter support

Issues of inconsistent use of interpreters by professionals, with health professionals “trying to manage without”, and problematic use of young people as informal interpreters, were raised.

“Doctors should check whether people need an interpreter while they are learning English and even when they have learnt it. They might need one sometimes.”

One participant shared a perception of resistance by some professionals to booking professional interpreter support. This is identified in national research as a significant issue, particularly when people have serious health problems and need to understand what is happening.

“Discussing things with the doctor is so important for my husband to be clear about what’s going on. There were times (hospital setting within the previous week) when the doctor had to remind the interpreter to interpret everything.”

There was feedback in one group discussion about perceived difficulties in relation to interpreting support provided within the last three months in Newcastle hospital settings, including unreliability and apparent lack of understanding of complex medical terms on the part of the interpreter. There were expressions of annoyance at the waste involved.

“I’d prepared lots of questions and I couldn’t do that because there was nobody to convey them to the doctor (booked interpreter did not arrive). I worry more now because I couldn’t tell the doctor my questions”.

“I said ‘dizzy’ and the interpreter said ‘headache’ in English.” (Person from an established minority ethnic community with high blood pressure and sufficient skill in English and experience of medical check-ups to notice the misinterpretation of a potentially significant symptom)

“Lots of time is wasted for the doctor and us. The consultation would be very fast with good quality

interpreting support. It delays treatment if they (interpreter) don't say the right thing”

These difficulties were communicated to the Trust in question and there was an immediate productive meeting with some community members and a commitment to following up the issues.

UK literature review: Research highlights the importance of professional interpreter support for some people with a first language other than English, so that they can access health and social care appropriately and use it effectively (Tribe and Thompson 2008, Cambridge 2007, Alexander et al 2004).

If people are not able to adequately describe their situations in social care consultations, and their symptoms in health consultations, diagnosis and treatment decisions may be affected (Bhatia and Wallace 2007).

This issue was identified by the Picker Institute in their analysis of the national baseline audit of cancer services for people from black and minority ethnic communities (National Health Service National Cancer Action Team 2010).

Investment in interpreting support therefore has a preventative aspect (Joule and Levenson 2008), in relation to avoiding waste of NHS resources through inappropriate medication, for example.

8. Changing commissioning

Interviewees working as practitioners, managers and commissioners reflected on the current change in the health and social care commissioning process as an opportunity to review the needs of the local population and match commissioning to them.

“While there might be small numbers of people from Black and minority ethnic communities registered with some primary care teams, there is now an opportunity to look across localities.”

Participants highlighted needs that may not ‘fit’ the way mainstream services are set up.

“Per capita funding doesn’t work for people who’ve arrived seeking asylum, because the primary care system relies on ten minute appointments and these people need a lot of support.”

“Conversations need to happen around people with protected characteristics (as outlined in the Equality Act 2010) who might need different input from services to get an equal result in terms of health outcome.”

There was acknowledgement that some communities have tended to be left out of strategic needs assessment, and that this needs to change. One participant highlighted the risk of some people at senior management level responding to the challenge of wider community involvement at a superficial level, ignoring the barriers that groups of people might face in becoming engaged in discussion with commissioners.

If you don’t have your communities engaged now, it could go to a judicial review. Business planning for GP commissioning consortia will include starting to look at working with all sorts of community groups.”

A series of community engagement events planned to March 2011 (North Tyneside Council and NHS North of Tyne 2010) will provide useful information (via analysis of monitoring data) about who is not yet ‘involved’.

“Services focus on people they ‘see’. We need to know who the people are who we don’t see, who we’re not geared up for, and how to get in touch with them. If you don’t meet people, how do you know what they need?”

One participant (practitioner, manager, commissioner) highlighted the importance of monitoring involvement in North Tyneside forums and networks (for example the Older People’s Forum and Disability Forum), particularly in terms of postcode and ethnicity, to see who is getting involved.

“Historically, we haven’t been good at patient and public involvement and partnership working. Patient groups tend to be white, better off and older.

People across communities perceived as 'hard to reach', are often keen to be involved but are not sure how to go about it, as illustrated by the quote below.

"I don't know how I can have a say. It's something I would like to know."

There was however a sense of "making inroads" in relation to developing relationships with people in black and minority ethnic communities, for example a feeling of progress in making links with women and men in the Bangladeshi community, and in African and Farsi-speaking communities. Examples were given of events that bring people together across communities, for example a session organised by North Tyneside Voluntary Organisations Development Agency (VODA) which was "a useful way of getting to talk with representatives from different groups".

People from minority ethnic communities suggested ways of extending and strengthening links.

"A good place to meet with and get information to women in African communities is hair salons and food shops. And there's going to be a future North Tyneside branch of the African Women's Support Network."

"Saturday mornings, at about 11am can be a good time to organise a meeting with people in minority ethnic communities who have a job."

"The Whitley Bay Islamic Cultural Centre will be a good point of contact when it is fully refurbished."

"There's an annual health event in Wallsend and some people from black and minority ethnic groups get involved in that."

"Wallsend People's Centre is very useful as a meeting point."

"We can sort a lot of problems together, listening to each other and helping each other."

Participants were asked to share their vision for North Tyneside service commissioning.

“My hope for the future is that we work together, for example to keep people out of hospital when they can be cared for at home. My vision is that we’ll have joint working groups in place by this time next year. We’ve started talking now and we can go on to plan and take action. We can produce a joint picture of people’s needs, rather than assuming we know what’s needed, and services can then fit that picture.”

“We need to identify groups of people and their health needs and, in parallel to that, scope non-traditional service providers, looking to see what’s around, particularly in relation to long term conditions. This would mean integrated work and community involvement. We need to be more creative and innovative in opening up a menu of services, and do it flexibly and quickly in partnership with others.”

“My vision is that in five years’ time we’ll know who our communities are and we’ll be working together, not just ticking a box any more.”

UK literature review: Literature highlights the potential of the analysis of local population diversity and development of community engagement, to inform collaborative commissioning (for example, Independent Advisory Group on Sexual Health and HIV 2009). Commissioners can ‘take a step back’ as suggested by Schehrer and Sexton (2010), to reflect on how they will connect and work with all users and potential users of services to produce a comprehensive strategic needs assessment.

The Social Care Institute for Excellence has identified people from Black and minority ethnic communities as one of four key seldom-heard groups (communitycare.co.uk 2008) and highlighted the value of making contact through trusted networks (Ali et al 2008, Refugee Council 2006).

Carlisle (2010:125) highlights the importance of investment of time in the process of supporting ‘representatives of dissimilar social worlds to learn to work together’. The reference to ‘dissimilar social worlds’ refers to power differences (in terms of who is able to do what)

between groups of professionals and majority and minority communities, which may explain some people's absence from community engagement activity.

Making things happen: Examples of Action

Action in the North East

- A Black and Minority Ethnic Advocacy Service was set up in North Tyneside in 2009 in response to low numbers of people from minority ethnic communities accessing public services. Weekly sessions at Wallsend People's Centre provide support for people as they face their day to day challenges (<http://www.iant.org.uk/groups.php>).
- North Tyneside is one of three sites in a national Year of Care pilot, due to end March 2011. Everyone living with diabetes is invited to be an active partner in their annual review with health professionals, discussing what they need to self-manage their condition over the next twelve months. An evaluation report will be available on the Diabetes UK and Year of Care websites.
- The Equality, Diversity and Human Rights Lead, Newcastle and North Tyneside Community Health, has systematically turned equality and diversity policy into practice across the organisation, for example, by identifying an Equality Champion in each service team.
NHS North East Equality, Diversity and Human Rights Group has produced equality fact files, for example Ethnicity and 'Race' (2008).
- Newcastle West End Community Development Consortium Knowledge Inclusion Project produced a leaflet 'All you need to know about refugees and asylum-seekers' (2005). It explains who refugees and asylum seekers are and where they are likely to have come from, gives an historical perspective on migration to the city, busts common myths and gives contact details for organisations providing support.
- A conference 'Reclaiming the Domestic Violence Agenda' was organised at the end of 2010 by Newcastle-based Angelou Centre to highlight the spectrum of domestic violence, including forced marriage and female genital mutilation, experienced by women in black and minority ethnic communities across the North

of Tyne area, including North Tyneside. The Angelou Centre hosts the regional Black Women's Domestic Violence Network. A conference report is being produced (www.angeloucentre.org.uk).

- Newcastle Health Improvement Service for Ethnic Minorities, HealthWORKS and Health and Race Equality Forum have worked together to take information about diabetes, blood pressure and support to stop smoking out to people in black and minority ethnic communities via places of worship.

Action across the UK

1. A national NHS initiative has involved some primary care trusts putting race equality at the core of their service planning and delivery (www.raceforhealth.org). Examples:

- South Birmingham Primary Care Trust recruited people from Black and minority ethnic communities to train to support parents of children with a severe disability.
- Liverpool PCT invested in training for staff in 97 practices to increase understanding about the importance of patient profiling. The aim was to cross-match coronary heart disease, diabetes and smoking status against patient profiling data, to identify where people are not getting the healthcare they need.
- Ealing PCT organised cooking classes for people in South Asian communities, who are more likely to develop diabetes than people in white communities. The cooking sessions encourage people to cook with less oil and salt and more vegetables, and build confidence in taking small steps to change.

2. The Delivering Race Equality Programme (Department of Health 2005) highlighted the need to improve access to the full range of psychological therapeutic support for people from black and minority ethnic communities, and established Community Development Worker teams in each local authority area. The North Tyneside CDW team was mentioned by several participants as an excellent resource for people in local black and minority ethnic communities.

3. A website has been launched, providing information and examples of good practice to support the integration of refugee families: <http://refugeeintegration.homeoffice.gov.uk/health/>.

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