HAREF CONFERENCE REPORT

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Introduction

120 people from Afghani, Pakistani, Chinese, Indian, Czech, Filipino, Slovak, African and Bangladeshi communities took part in the fourth HAREF conference on 7 June 2010 at the Assembly Rooms in Newcastle upon Tyne\(^1\). It was an exciting event and there was very positive feedback about the opportunity to come together and discuss things that affect people’s health and wellbeing and the information and support that they need to stay as healthy as possible.

The Health and Race Equality Forum Chair, Shamshad Iqbal, the Development Worker, Dipu Ahad, and the Coordinator, Ann McNulty, want to say a big “thank you” to everyone who was part of the conference. A particular “thanks” to the:

- Groups of people from different minority ethnic communities who took the time to get together with others on the day
- Workers who supported groups and individuals to take part
- Health Improvement Service for Ethnic Minorities, HealthWORKS and the Newcastle Stop Smoking Service, for planning the conference with the HAREF workers
- Interpreters from the Newcastle Interpreting Service
- People who facilitated group discussions and those who took notes
- Commissioners, senior managers and others in strategic positions who came to the conference to meet people from a range of minority ethnic communities and listen.

\(^1\) Some of the photographs taken at the conference, with people’s permission, are reproduced in the report.
What is HAREF?

- HAREF is the Health and Race Equality Forum, a network linking diverse minority ethnic communities across Tyneside to maximise wellbeing and health.

- HAREF is one of the areas of work of Newcastle Healthy City, which is part of the World Health Organisation and aims to reduce inequalities.

- HAREF supports people in Black and minority ethnic communities to have a say about what’s working well in the provision of health care in its broadest sense, to identify gaps and areas for improvement, and to take action.

- HAREF produces information bulletins and organises events that bring people together to discuss ways to reduce health inequalities and maximise people’s wellbeing.

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2 The HAREF network has existed since 2000, when Newcastle Health Action Zone identified ‘health and race equality’ as an area of special action. Northern Rock’s two year investment, 2006-2008, supported the forum to develop and attract sustainable funding, and the network has expanded to include communities in other parts of the North East. HAREF is funded by NHS North of Tyne and income is generated through training and research.

3 The World Health Organisation (WHO) has influenced people’s understanding of health in the broadest sense. The Declaration of Alma Ata at the 1978 International Conference on Primary Health Care acknowledged the profound effect of economic and social inequalities on people’s health and wellbeing, and a new approach to public health in the 1980s included the Healthy Cities movement. The impact of inequalities has continued to be explored, for example by Acheson in 1998 (Independent Inquiry into Inequalities in Health Report, London: The Stationery Office), and by Wilkinson who highlighted in 2006 that some people’s lives are shorter and more stressful because of income inequality (The Impact of Inequality, London: Routledge).
What difference does HAREF make?

- HAREF encourages people to access services, for example preventative services such as flu vaccination and cancer screening.

- Outcomes of the work of the forum are increased knowledge of services in the short term and improved quality of life at all life stages in the longer term.
Areas for action

The people who took part in the conference discussed things that affect their health and wellbeing, and the information and support that they need to stay as healthy as possible.

The seven areas of action outlined below were identified in all or the majority of group discussions.

Potential action will be discussed at the next HAREF meeting in September 2010.

The participation of people from diverse minority ethnic communities highlighted different issues for people in established communities and those who have arrived recently who are often referred to as ‘migrant’ and ‘emerging’. For example, people from the Chinese community talked about the value of the Chinese Healthy Living Centre as a source of opportunities for exercise, singing, cooking with healthy ingredients, and getting information e.g. about stopping smoking. They highlighted the insecurity of funding for this important resource. The issue of how to fund community-led activities that contribute to achieving the national\(^4\) and local vision for improving people’s health needs urgent discussion.

For people who have arrived more recently, getting to know how the health and social care system works is one of the most important issues. Different groups identified particular needs, for example First Aid training for the Afghani community. Discussion about the impact of cuts to funding for work that supports migrant communities is urgent.

\(^4\) Department of Health (2010) Equity and Excellence: Liberating the NHS.
1. Appropriate and consistent use of interpreting support

- Issue of interpreters not being booked, particularly for hospital appointments, creating a barrier to understanding what is being discussed in consultations with nurses, doctors and other health professionals. One person highlighted the excellent quality of clinical care in hospital, particularly the care provided by nursing staff, and added: “but there are severe problems accessing interpreters”, referring to the whole system of booking. Others said: “The hospital says the GP should organise it, the GP says the hospital should organise it”; “No interpreter at hospital appointment so not understood”; “Often sent home from hospital appointment without being seen”

- Importance of interpreter support during emergency care e.g. at Accident and Emergency

- Anxiety about not being able to express what is wrong without interpreter support

- Importance of quality of interpreter support e.g. through adequate level of training and management.
2. Appropriate and consistent use of advocacy support

- “Some people need advocacy support in consultations to discuss things fully”.
3. Making sure people know how the NHS works

People identified the need for clear information about the different parts of the NHS (Primary, Emergency and Maternity Care):

“It’s really hard work accessing health professionals”.

To use primary care effectively, people need to know:

- How to use NHS Direct and Walk-In Centres “to avoid calling out the emergency GP”
- What to do if you are not well enough to go to the GP
- What documents etc Health Centres need when people register. This is of particular concern for people who have arrived seeking asylum
- When to go to see a primary care nurse or doctor: “I only go when in a lot of pain”; “Don’t bother with going to the doctors”
- What choice people have to see a female or male GP
- How to make a primary care appointment e.g. to avoid unnecessary use of the ambulance service
- How to make an urgent appointment
- Whether it is possible to have a reminder about a GP appointment.
To use emergency care effectively, people need to know:

- When to call an ambulance: “Feel confused about this”. “Worried about a family member and afraid they might die”

- What information you need to give about yourself at the Accident and Emergency department

- How to communicate with the emergency services.

To use maternity care effectively, people need to know:

- When to go to hospital if you think you are in labour e.g. to avoid calling an ambulance

- What to do if it appears that a woman is miscarrying e.g. confusing information in a hospital letter about when to call an ambulance.
4. Getting the most out of health consultations

For people to get the most out of consultations with health professionals there is a need for:

- Clear information about treatment offered, for example the effectiveness of different forms of medication for pain relief: “Because of my pain my mood goes down”. A lot of people said they are confused when GPs prescribe paracetamol and need more information about how that works for some conditions.

- A level of communication that helps people to feel taken seriously and not “brushed off” e.g. more detailed explanation of conditions and reasons for referral or non-referral to secondary care: “I have back pain and am anxious about something serious having been missed”.

- Brief information about what will happen at hospital appointments.

- Need for more information about why tests are carried out, the time required for results, and how results will be communicated.
5. Taking health information and support out to people.

There was general consensus about the value of bringing health information and support ‘out’ to people in venues they are familiar with and feel comfortable in, rather than waiting for them to come ‘in’ to services: “Making it more active, fun and enjoyable”; “We can help each other and learn together as a group”; “It would be good if health workers came to a community centre or place of worship to support us”; “Information is best given to small groups within the community”.

This is linked to the importance of people avoiding becoming isolated by getting out of their homes and having opportunities to meet other people and to access information, at community events, drop-ins and various social groups. ‘Health talks’ can increase people’s self esteem and boost their confidence to use services appropriately: “I stay in the house and feel helpless about asking for support”.

The importance of help for some groups of people e.g. those with mobility problems or with mental ill-health, to get out of the house and make their way to different venues, was highlighted.

Targeted women-only and men-only sessions were also identified as a useful way of encouraging people to start to take part in activities.

One specific suggestion was: “Circulate information about Active Newcastle at Kenton Leisure Centre every Sunday”. The importance of people being signposted to a range of services and support was also identified. The HAREF network was identified as one effective way for people in minority ethnic communities and professionals who work with them to get information about what’s going on.
The following information and support needs were identified in the majority of group discussions, with people stressing the importance of clear information about a range of things to do with health and well-being, using appropriate language(s) and other media e.g. visual and audio resources, digital technology and written information where requested:

- How to manage diabetes: “People may not be aware they have diabetes until told by the GP when visiting for other reasons”; “People might choose to ignore their symptoms”; “Would like information sessions to raise awareness and reduce inequalities”; “Need to change people’s mindsets”. There was reference to the Ramadhan prayer calendar with information about how to manage diabetes during periods of fasting, which has opened up discussion about the facts and the taboos: “Looking at how this works from both a religious and NHS perspective”

- Affordable opportunities for getting enough exercise and staying mobile: “I want to keep active and fit. It’s important I am healthy to look after everyone”; “If I’m OK, then everything will be OK”

- Food and eating to stay healthy, including information about how food is produced e.g. genetic modification and use of hormones. There was a specific request for African women’s cookery sessions.

- Mental health and wellbeing: “There is reluctance to talk about it”; “Mental health issues not openly discussed”. “Want to know what to do about (younger male family member’s) mental ill-health”; “Bereavement and how that affects mental health”. The need for information about, and support for people experiencing, depression, including post-natal depression was mentioned specifically, as was the significance for some people of spirituality: “Depression is not recognised in our community or understood”; “People have a lot of tension, worries and pressure and their faith and spiritual life helps”
• Support to stop smoking.

• Stress: “Stress turns into depression”; “Was told to just get on with life”

• Care and support during terminal illness eg Macmillan Nurses and Marie Curie Centre

• Screening for disease e.g. bowel cancer screening and high blood pressure measurement. Most of the women in one of the discussion groups had been screened for breast cancer, but others highlighted that “services are provided but are not always taken up”; “Young women need to be encouraged to attend screening”

The following information needs were highlighted in some, though not all, group discussions:

• How to manage continence difficulties: “Need to be more openly talked about”

• How care in the community works

• Domestic violence

• Sexual health

• Supari addiction: “Not many people are aware of the risks”
• Young people starting to drink alcohol at an early age

• Support for parenting eg around managing behaviour

• Arthritis

• Heart disease e.g. cholesterol and what to eat

• Pain management, particularly in relation to back pain

• Personal budgets: “Don’t know anything about them”

• Symptoms of dementia: “Could someone visit Chinese Health Centre to talk about dementia”

• Early detection of thyroid problems
6. Training for professionals

Training for health and social care professionals to include:

- Discussion of perceptions of communities and people from different cultural backgrounds

- Awareness-raising about the implications of relationship and family break-ups in terms of isolation and mental health e.g. in relation to arranged marriages

- Exploring own attitudes

- Understanding the reasons for people’s embarrassment around some things

- Communication skills and the importance of appearing welcoming and approachable

- How to work with advocates

- How to work with interpreters and when to use telephone or face to face interpreting support

- How to work in a way that maintains people’s dignity

- Recognising the importance of not making assumptions e.g. about parenting practices.
7. Monitoring

- “We have to tick ‘other’ on monitoring forms”. There is a need to build a more sophisticated picture of the people who live in Newcastle and use local services.
Things that affect people’s emotional and social well-being

- Keeping problems within the family and not sharing them with anyone else
- Racism e.g. name-calling and stereotyping
- Housing conditions: “Shocking”
- Lack of employment opportunities and discrimination in job recruitment: “Difficult for BME people with high qualifications to get fair access to higher level jobs”
- Lack of resources
- Being a carer “I look after my son – he’s in a wheelchair. My husband is ill as well. It’s hard work”; “Can’t leave my son, who is disabled, alone. No respite available for me. It’s hard to rely on family all the time”; “No one from outside the family helps us. I don’t know what’s available to me”; “I go to bed at 1am and get up early”. “Caring is hard work physically and mentally”; By contrast, one person said: “I do have family support and don’t need outside help”. There was also appreciation of social worker support, though some people were not aware of how to access this.

- Effects of crime and anti-social behaviour
• Family relationships, parenting needs and intergenerational issues.
• Domestic violence
• More activities for children so they are not wandering around the streets
• Avoiding licensing for alcohol sales in areas where it causes problems
• The local environment, for example the condition of roads, rubbish collection and dogs fouling pavements. People in some of the groups said they would like to meet with Newcastle Council to discuss community volunteering to tidy up the streets.