

'Seldom Heard' Report - Involving and Consulting Hard to Reach Equalities Patient Groups

**A report by Berkeley Wilde, Minotaur Communications
Commissioned by North Bristol Hospitals Trust
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Organisations

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1. Introduction

'Seldom Heard?' - Involving and Consulting Hard to Reach Patient Groups is a report written for the North Bristol Hospitals Trust (henceforth NBT). NBT has objectives to develop a strategy/action plan engaging with a range of statutory and voluntary sector partners to promote engagement with user groups, including those which it has defined as 'hard to reach', and to regularly review progress against this strategy/action plan.

In March 2010, NBT commissioned Minotaur Communications, an independent research and management consultancy, to carry out a SWOT analysis and develop an action plan in relation to involving and consulting 'hard to reach' equalities patient groups. This report presents the findings relating to these objectives.

2. Definitions

For the purposes of this report 'hard to reach' or 'seldom heard' equalities patient groups are defined as groups relating to:

- **Age** (Children and Young People and Older People)
- **Black, Asian and Minority Ethnic** (henceforth BAME)
- **Disability**
- **Gender**
- **Gender Identity** (henceforth Trans)
- **Lesbian, Gay and Bisexual** (henceforth LGB)
- **Religion or Belief**

(Source: Equality and Human Rights Commission)

The project management team agreed to include the following communities and groups within this definition: Roma Gypsy/Irish Travellers, Language, Women's Health/Men's Health, Learning Difficulties/Learning Disabilities, and Mental Health.

- **Consultation** – the definition of Consultation within the purview of this project is; any formal consultation, engagement or involvement activity carried out with 'hard to reach' or 'seldom heard' equalities patient groups.

3. Aims

- To map what consultation/involvement exercises have been carried out since 2005 with hard to reach groups within NBT and externally.
- To carry out a SWOT analysis on NBT services engaged with this hard to reach activity.
- Determine how the outcome of this work has influenced NBT policies, action plans etc. within a directorate, department or Trust wide.
- Identify best practice and make recommendations to NBT.
- Draw up an action plan to support the development of the Patient and Public Involvement Strategy an Equalities work based on the findings and on best practice identified.
- Provide final report and recommendations on how to involve and consult hard to reach patient groups within the purview of the Patient and Public Involvement Strategy and Equalities work. (Henceforth PPI).

4. Methodology

Between March and July 2010 interviews were carried out with service managers and staff including:

- 10 x face-to-face interviews with health service managers and staff across (Bristol and South Gloucestershire) NHS Trusts (first round interviews).
- 10 x face-to-face interviews with service managers and staff across the (Bristol and South Gloucestershire) voluntary sector (first round interviews).
- 10 x telephone interviews with service managers and staff from statutory and voluntary sector health organisations (second round interviews, identified from first round interviews).
- A total of 30 interviews.

NB. Appendix 1 – Interview Questions (Page XX)

5.0 Consultation Mapping

The following consultation and engagement activities provide a snap-shot of activities across the sub-regional health community during the period 2005-10. This does not represent **all** of the engagement activities, but provides a mapping of examples of activities over the last five years. Consultations have been broken down by equalities strands including; Generic Equality and Diversity, Age, BAME, Disability, Gypsy and Travellers, LGBT, Religion or Belief, and where consultations have taken a cross-cutting equalities approach.

5.1 Consultation Mapping – Generic Equality and Diversity

- 'Count Me In' demographics of users including equalities groups. (2009) A snap shot of services from an equalities point of view, and equalities monitoring. Contact: Hildegard Dumper, Bristol Community Health (email) Hildegard.Dumper@bristolpct.nhs.uk
- Annual Patient Satisfaction Survey. Each service each year carries out a patient satisfaction survey, includes an equalities monitoring form. Contact: Hildegard Dumper, Bristol Community Health (email) Hildegard.Dumper@bristolpct.nhs.uk
- Bristol Health Services Plan (BHSP), (2005-06) Consultation on the Bristol Health Services Plan (Bristol and South Gloucestershire). A reconfiguration of how the health service operates; more community-based hospitals and activity, services being more specialist. Bristol PCT involved in consultation around the BHSP, including sessions on working with seldom heard groups. Contact: Tony Watkin, UH Bristol (email) Tony.Watkin@UH Bristol.nhs.uk
- The redevelopment of Cossham Hospital: As part of the consultation for redeveloping services in Kingswood (2006), extensive work was done to engage with seldom heard groups including carers and disabled people, mental health service users, parents with young children/new parents, young people, lesbian & gay people, and black and minority ethnic communities. For more information on this project, please contact Paul Frisby (paul.frisby@sglos-pct.nhs.uk). Following this formal consultation, the project to redevelop Cossham Hospital has continued to work with and involve local people and public representatives in the project.
- Joint Strategic Needs Assessment (2009). NHS South Gloucestershire and South Gloucestershire Council consulted the public in South Gloucestershire on how to ensure people of all ages can enjoy good health and well-being. The consultation focused on the changes that happen in people's lives – for

example, children growing into adults, becoming a carer, losing a job, retiring or bereavement – and aimed to find out what kind of support people need at these times. It also looked at how people access services and any inequalities in the levels of health enjoyed by different sections of the community. The results have fed into the Joint Strategic Needs Assessment (JSNA), a document which will be used to shape decisions about how care services are planned and delivered in the future. The consultation team asked for people's views at a wide range of events and locations, including shopping centres and festivals, and gave people the opportunity to feed back in a variety of ways. Contact: Louise Winn, NHS South Gloucestershire (email) Louise.Winn@sglos-pct.nhs.uk

- Out of Hours Review: As part of our current review of out of hours, we have canvassed the views of stakeholders including the South Gloucestershire Black and other Minority Ethnic Communities Liaison Group to hear about people's experiences of current services and ideas for future improvement. Contact: Louise Winn, NHS South Gloucestershire (email) Louise.Winn@sglos-pct.nhs.uk
- Feedback from people in custodial services: South Gloucestershire Patient Advice and Liaison Service is working in partnership with the South Gloucestershire Local Involvement Network (LINK) and the Independent Complaints and Advocacy Service (ICAS) to develop a way for people in custodial services in South Gloucestershire to provide feedback on their health services. Workers from each agency visited the health centre at Eastwood Park Prison, spoke to the women prisoners and asked them about their health services and how they think they could feedback effectively to LINK, PALS and ICAS. The health services manager and health centre practice manager support this work, which will develop over the course of 2010. Contact: Louise Winn, NHS South Gloucestershire (email) Louise.Winn@sglos-pct.nhs.uk
- Eastwood Park Prison Health Centre. (2010) (South Gloucestershire LINK) Contact: Pat Foster (email) PatFoster@thecareforum.org.uk
- Engagement and Involvement Plan involving hard to reach equalities groups. (2009) Contact: Pat Foster, South Gloucestershire LINK (email) PatFoster@thecareforum.org.uk
- South Gloucestershire Community Engagement Strategy. (2008-11) Contact: Pat Foster, South Gloucestershire LINK (email) PatFoster@thecareforum.org.uk
- Bristol Health Services Plan consultation (2003-04). Cossham and Frenchay hospital consultation led by The Care Forum. Contact: Kate Oliver, The Care Forum (email) KateOliver@thecareforum.org.uk
- Bristol NHS Organisations: Engaging with Communities for Equality Stakeholder Workshop (2007) Contact: David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk
- Maternity and New Born Services review, extensive period of consultation and engagement with the local community and public. Broken down into 'hard to reach' groups. Consulted with Gypsies and Travellers, people with learning difficulties and fathers.

5.2 Consultation Mapping – Age - Children and Young People

- 'Your Say On Health' Consultation with Children, Young People and Parents in Bristol and South Gloucestershire to Inform the Development of a New Community Children's Health. Barnardos and NBT (2008). Contact: Emily Roberts, Barnardo's (email) emily.roberts@barnardos.org.uk

- Participation event held to give young people an opportunity to express what they need and want from the healthcare services they access, and work towards achieving the Every Child Matters outcome; Make a positive contribution. (2010) Contact: Emily Roberts, Barnardo's (email) emily.roberts@barnardos.org.uk
- Knowle West Media Centre – Digital Fish Young People's Group – exploring health issues with young people (2009) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Young Carers Project: consultation with young carers (2009) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Youth Council working with UH Bristol Governor and Board. Contact: Tony Watkin, UH Bristol (email) Tony.Watkin@UHBristol.nhs.uk
- Bristol Health and Social Care Network (2009) Transition - Children to Adult Services. Contact: Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk

5.3 Consultation Mapping – Age – Older People

- Bristol/South Gloucestershire Older People's Network (2010) Care Provision for BME Elders. Contact: Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol/South Gloucestershire Older People's Network (2009) Falls Prevention. Contact: Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol/South Gloucestershire Older People's Network (2009) Daycare. Contact: Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol/South Gloucestershire Older People's Network (2009) Dementia Strategy. Contact: Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol/South Gloucestershire Older People's Network (2010) End of life care. Contact: Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Better Support For Older People, Formal Consultation Plan (2009). Contact: Kirsty Eastham, South Gloucestershire Council (email) Kirsty.Eastham@southglos.gov.uk

5.4 Consultation Mapping - BAME

- Somali Health Awareness Day. Contact: Hildegard Dumper, Bristol Community Health (email) Hildegard.Dumper@bristolpct.nhs.uk
- Somali Women's Voice community radio programme. Contact: Hildegard Dumper, Bristol Community Health (email) Hildegard.Dumper@bristolpct.nhs.uk
- Bristol City Council website for Somali community
<http://www.bristol.gov.uk/ccm/content/Community-Living/Equality-Diversity/talking-cultures-dvds/talking-cultures-somali-community.en;jsessionid=AA9B2144E704E8696030E81E95307ABE.tcwwwaplaws2>
- Health and Social Care Related Workshops and Discussion on Health and Social Care for Somali Women (2010). Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- 'Walking the way to breast screening', the experiences of BME women (2009). Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk

- Study to explore the needs of the Asian Community in relation to structured diabetes education, focus groups in Asian languages (2009). Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk
- Black and other Minority Ethnic Communities Liaison Group (BoME) - NHS South Gloucestershire co-chairs the BoME group with South Gloucestershire Council. The group's purpose is to identify and eliminate barriers for people in minority ethnic communities; encourage and empower people to access services; and to ensure services meet culturally appropriate needs. Contact: Louise Winn, NHS South Gloucestershire (email) Louise.Winn@sglos-pct.nhs.uk
- Bristol Race Equality in Health and Social Care Partnership (BREHP), a local partnership of BME voluntary sector organisations, NHS and local authority statutory agencies – Bristol PCT coordinated this from 2002 to 2008 to work towards racial equality in the planning, commissioning and delivery of health care in Bristol. Contact: David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk
- The Black & Minority Ethnic (BME) Customer Service Project – (2007-08), this initiative developed a series of local reporting centres, so that comments, concerns and complaints about NHS services could be made to BME voluntary sector organisations, who would coordinate and forward them, (anonymously if required) to the relevant NHS organisation. This has continued as a mainstream initiative coordinated by the PCT's PALS team. Contact: David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk
- BME Community Development Workers – coordinated by the PCT, these workers have been recruited and deployed by a group of statutory and voluntary sector organisations to identify challenges, advocate for and implement changes to reduce ethnicity-based inequalities in mental health care. Contact: Mohammed Elsharif (email) Mohammed.Elsharif@bristol.nhs.uk
- Facilitating the making of a film following one man's quest to regain his life after a stroke Contact: Mohammed Elsharif (email) Mohammed.Elsharif@bristol.nhs.uk
- Facilitating the launch of the weekly "Healthy Living Show" on the Ujima community radio station, giving a voice to individuals, small groups, charities, voluntary and statutory agencies to promote their services, experiences and key health messages to a mainly BME audience across Bristol. Contact: Mohammed Elsharif (email) Mohammed.Elsharif@bristol.nhs.uk
- Hosting a "Race, Identity, Inequality and Mental Health" Question Time event at which BME service users were able to articulate their experiences and concerns to a panel of local service providers and academics. Contact: Mohammed Elsharif (email) Mohammed.Elsharif@bristol.nhs.uk
- Hosting a Chinese Mental Health Day and Somali Mental Health Day, the latter giving community members an opportunity to explore mental health and wellbeing and its relationship to Islamic spirituality. Contact: Mohammed Elsharif (email) Mohammed.Elsharif@bristol.nhs.uk
- Involving BME mental health service users in delivering Race Equality Cultural Competence training to senior NHS staff from a range of primary care organisations. Contact: Mohammed Elsharif (email) Mohammed.Elsharif@bristol.nhs.uk

- Facilitating the involvement of BME service users and members of the public in the Maternity Services Review, visits by Senior NHS/voluntary sector staff to BME community organisations and Gypsy/Traveller sites and advocating around access to “women only” swimming sessions at a local public swimming pool. Contact: Mohammed Elsharif (email) Mohammed.Elsharif@bristol.nhs.uk
- People First Black Members’ Group (a support and advocacy group of BME people with learning difficulties) (2008) Contact: David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk
- BME Young People Participation Project, Barnardo’s and NBT (2010) Contact: Emily Roberts emily.roberts@barnardos.org.uk
- BME Carers in South Gloucestershire - The next Five Years. The New South Gloucestershire Carers Strategy (2010). Contact: Kirsty Eastham, South Gloucestershire Council (email) Kirsty.Eastham@southglos.gov.uk

5.5 Consultation Mapping - Disability

- Action for the Blind, Bristol and South Gloucestershire LINK. Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Bristol Pacesetters: Deaf and Wellness: a story of community engagement and empowerment in Bristol (2009). Contact: Christina Gray, NHS Bristol (email) Christina.Gray@bristol.nhs.uk
- Health & Adult Social Care Scrutiny Committee and Bristol LINK Dementia Strategy Event (2010) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Disability Equality Forum and Bristol LINK Joint Event (2009) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Mental Health Open Space event (2009) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Listening Partnership/WECIL disabled young people and young people with learning disabilities (2009) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Website development group improving accessibility for visually impaired people, consulting with Action for Blind. Contact: Tony Watkin, UH Bristol (email) Tony.Watkin@UHBristol.nhs.uk
- Disability equality scheme and action plan: In developing our Disability Equality Scheme and action plan for 2009 – 12, an event was held with members of the South Gloucestershire Disability Equality Network last summer to ask people about their experiences of health and council services. Contact: Louise Winn, NHS South Gloucestershire (email) Louise.Winn@sglos-pct.nhs.uk
- The Disability Equality Advisory Group (a time-limited group of disabled individuals and voluntary sector organisations) (2008) Contact: David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk
- Bristol Health and Social Care Network (2008) Disability Equalities/The Referral Pathway. Contact Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol Mental Health Network (2010) Mental Health and Stigma. Contact Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk

- Bristol Mental Health Network (2010) The Bristol Vision for Mental Health and Dual Diagnosis Strategy. Contact Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol Mental Health Network (2009) Increasing Access to Psychological Therapies in Bristol/User Focused Monitoring. Contact Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol Mental Health Network (2009) Delivering Race Equality (Gypsies and Travellers). Contact Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- Bristol Mental Health Network (2009) BAME ('Count Me In') and Mental Health & Wellbeing. Contact Leon Quinn, The Care Forum (email) LeonQuinn@thecareforum.org.uk
- 'Big Health Check Day', annual event led by the Learning Disability Service, engaging and consulting people with Learning Disabilities talk about their health issues, and what they think about healthcare. NHS Bristol and NHS South Gloucestershire.

5.6 Consultation Mapping – Gypsies and Travellers

- Assertive outreach research project – 'Do Gypsies, Travellers and Show People get the support they need with stress, depression and nerves' Report by Bristol Mind (2008) Contact: Annie Crocker, Gypsy and Traveller Team, Bristol City Council (email) annie.crocker@bristol.gov.uk
- Pacesetters Programme (2010), South West Strategic Health Authority, Bristol PCT, South Western Ambulance Service NHS Trust. Improve Gypsy and Travellers access to local services, Staff Cultural Awareness raising, Raising awareness among Gypsy and Traveller Communities, Develop a model of Gypsy and Traveller Participation in the promotion of health and well being, Raising awareness among Gypsy and Traveller Communities. Contact: Michail Sanidas, NHS South West (email) Michail.Sanidas@southwest.nhs.uk
- West of England Gypsy, Traveller and Show People Accommodation Assessment (2007) Contact: Annie Crocker, Gypsy and Traveller Team, Bristol City Council (email) annie.crocker@bristol.gov.uk

5.7 Consultation Mapping – LGBT

- 'SO Heard' - the experiences of Lesbian, Gay, Bisexual and Transgender people working in the NHS in Bristol. (2009) Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk
- LGBT staff Network set up as a result of the 'SO Heard' report. Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk
- LGBT champion at board level. Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk
- Sexual Orientation & Health Stakeholders Group. (SOHSG) Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk
- 10 LGBT Equality Standards. Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk
- Bristol LGB Pride event. (2010) Contact: Clive Gray, NHS Bristol (email) Clive.Gray@bristol.nhs.uk

5.8 Consultation Mapping – Religion or Belief

- Council of Bristol Mosques. Working with the Bristol Council of Mosques, bringing all the Bristol Mosques together in one place, working with them to develop policies, directly inform policies, easier for people who use the mosques to feel that they have access to information. Contact: Tony Watkin, UH Bristol (email) Tony.Watkin@UHBristol.nhs.uk
- Bristol Male Circumcision Project – (2007-08) Bristol PCT facilitated a dialogue between representatives of the local Muslim community and health care providers around the development of affordable and safe male circumcision services in Bristol. A non-NHS funded service was eventually developed by a local GP, supported by a leaflet and an ongoing health promotion campaign by the PCT around how to access safe circumcision services. Contact David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk

5.9 Consultation Mapping – Cross-Cutting Strands

- Freedom Youth – consultation with Lesbian, Gay, Bisexual young people (2009) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Muscular Skeletal Service (MSK) issues from patient focus groups, mostly attended by BAME and Older People's groups (2009-10) Contact: Caroline McAleese, Bristol LINK (email) carolinemcaleese@linkbristol.org.uk
- Bristol PCT conducted a series of consultation and involvement exercises in 2008 aimed at informing the priorities within the Single Equality Scheme and action plan 2009-2012, as well as raising awareness about what the scheme is trying to achieve. Contact David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk
- 'Towards a More Caring City' (2006) Report of the Citizens' Jury on research priorities for Bristol Primary Health and Social Care. Contact David Harris, NHS Bristol (email) David.Harris@bristol.nhs.uk

6.0 SWOT Analysis

6.1 Strengths

- Good personal contacts within BAME communities, religious minority communities and within local equalities groups for women and older people, to promote opportunities, contact and involve groups.
- BAME communities well represented in Patient & Public Involvement consultations.
- Chinese community organisation strong, especially in South Gloucestershire.
- Work with Somali community, especially NHS Bristol, especially with Somali women.
- Disabled people and communities well represented in Patient & Public Involvement consultations.
- Building up a reputation as an organisation which is interested in the views and perspectives of a range of stakeholders, including patients from a variety of communities.
- Feedback from consultation, engagement and involvement activities demonstrate that people appreciate the opportunity to have their voices heard.

- Making links with people, especially with communities.
- Excellent work with LGB & T communities by NHS Bristol
- Raised awareness of equalities monitoring (e.g. 'Count Me In'), Bristol Community Health.
- When you show energy, enthusiasm and commitment, community groups will really work with you.
- Community empowerment.

6.2 Weaknesses

- Some areas of work consultation is strong, other areas it's weak
- Duplication of work
- Work not being "joined up"
- Daytime consultation meetings and events – creates inaccessibility
- Lesbian, Gay, Bisexual communities and groups under-represented in PPI
- Women's health under-represented in PPI
- Men's health under-represented in PPI
- Religion or belief – very little specific PPI, sometimes added on to BAME
- Difficult to engage with Religion or Belief groups
- Trans communities and groups – no specific PPI
- Difficulty engaging with young people
- How young people are treated, especially in primary care
- Hospital food (not culturally relevant, especially to the Sikh and Black African Caribbean communities)
- Hospital food (patients not knowing they have choices)
- Only delivering (resources) in English
- Some groups are easy to access, others are 'harder to reach'
- Deaf community under-represented
- Getting information out about what's available.. "I didn't know that (service) existed"
- Does this represent systematic, ongoing engagement and involvement with (hard to reach) such communities?
 - "Whilst, as individuals, we often have ongoing dialogue and communication with individuals from "hard-to-reach" communities, it might be going too far to say that this represents systematic, ongoing engagement and involvement with such communities."
- The time (in terms of human resource capacity) which it takes to arrange an activity/event/initiative.
- Demonstrating tangible and/or measurable outcomes as a result of engagement is difficult.
- Encouraging people to get actively involved.

- Seldom heard communities don't necessarily speak to each other.
- Very little participation from young people.
- Everything is often paper based with consultations, this is not always accessible.

"It is sometimes difficult to get NHS organisations on the same page at the same time, so that we are still undertaking many individual initiatives, rather than joining them up ... the public sees us as "The NHS", rather than as individual NHS organisations..."

6.3 Opportunities

- NBT/UHB/PCT/BCH doing more together, cross-cutting partnership approach to Equality & Diversity PPI
- Planning and coordinating PPI consultations across local NHS

"For example, one of us could go and meet with Dhek Bhal, on behalf of the partners (the local NHS) and talk about what issues and barriers the group wants to raise, which could be of relevance to other NHS Trusts. Rather than having four different people having appointments with the group in one month and then never hearing from any of us for a year. We could all be a bit more co-ordinated in terms of how we're engaging and how we're informing others. I think we need to map out who are the people we are actually engaging with, and where the gaps are. It is also important to consider best practice from other areas."

"It's a finite community we are working in and we're all doing similar things. The worse thing that could happen is on a Monday UH Bristol with Dhek Bhal, on a Tuesday NBT is with them, and on a Wednesday NHS Bristol is with them, and then they say "it's not joined up". I know we do joint work, we do things together, I think we can work together more, and plan a bit better."

- Champions representing each equalities group/all seven strands at board level
- Ambassadors within communities
- One website portal across the local NHS

"We have talked before about having some information on the Bristol Health Services Plan website. It's almost like we need a portal where we can share what we are up to, like a diary of what is coming up, so you could click onto the diary and Bristol are meeting with a group, we could either join up with that or ask them to feedback on any issues. That's where we need to get to."

- Communities value services going out to them e.g. outreach
- Focus groups/open space events – what needs to be done differently?
- Coordination and consolidation of activities
- BAME, gypsy & traveller communities, young people, mental health, learning disability, learning difficulty improving PPI
- Community radio good at reaching hard to reach (especially) BAME communities and groups

- Asian speaking peer education needs resourcing
- Community language interpreters
- BSL interpreters

“The BSL Forum are working with staff at NBT looking at access to BSL interpreters that are trained to a specific level to be able to deal with health language, obviously it’s really complicated, a lot of health terms can be quite hard to understand, and trying to translate that into sign language needs to be very accurate and clear rather than just directly translating a word, and that’s come up that interpreters aren’t always trained to that level and that’s come up a few times with interpreters as well, there are sometimes specific health terms that aren’t being interpreted very well. Also the access to interpreters for community languages, people are not always aware that they can do that.”

- Marketing campaigns on buses
- PPI consultation events in rural communities
- PPI Forum e.g. LINK’s
- Morning, afternoon and evening PPI meetings and events, improving accessibility
- Building relationships with commissioners e.g. LINK’s
- Information available in a variety of formats
- Regular Equality & Diversity training for all staff covering all seven equality strands
- Raised awareness of equalities monitoring amongst patients and staff
- Equality Update quarterly newsletter coordinated on behalf of local NHS partners by Bristol PCT/BEHP
- Customer Service Experience Project
- More coordination by the PCT of efforts to consult and involve, avoiding consultation fatigue, but also developing long-term and trusting relationships with communities
- Financial incentives to encourage people to take time out of their busy lives to engage
- Demonstrating a direct link to show how patient engagement/involvement has impacted on the way services are delivered.
- Reach hard to reach through front line workers, make much better use of that.
- A seamless ‘joined up’ service, if anyone is out there doing an event, bring it back to the partnership.
- Raising awareness of different equalities issues.

“The need to engage with a wide range of patients, and the feedback from patients which we have received, has improved our understanding of how we are generally perceived as one NHS. This has opened up opportunities for better joined up working around community engagement and communication.”

- Listening to people is what it’s all about..

"Listening as organisations. Bristol is rich in information about different experiences of different communities, pouring in all the time. Really listen and act on this, not doing this as fast and as well as we could. What are the gaps, partnership/joined up, share information. What is harder is to reach within the organisations, make sure our organisations are hearing and responding, to push through issues and concerns in the right way."

6.4 Threats

- Budget, Resources and Time
- Difficulty in getting people involved in PPI
- Concerns around accessibility
- Having carried out consultations, delivered reports, communities yet to see changes
- Time it takes to trickle down
- Large rural area (e.g. South Glos.)
- 'Hidden' hard to reach/seldom heard groups within the community
- This type of work is often perceived as an add-on or burdensome: the responsibility of someone else and an inconvenience in terms of real (and highly-pressured) jobs
- Attitudes and resources
- Raising and maintaining the level of awareness required by policy makers and practitioners if services and functions are to result in equitable access and health outcomes, regardless of personal characteristics.
- NHS workers are still fearful about being perceived to "favour" one community over another.
- Getting people to understand that we have legal duties to eliminate the type of built-in discriminatory practices and outcomes that have accumulated over decades or centuries is still a difficult task.
- Training has a potentially significant role to play and the continuing challenge for equality and diversity training programmes is how to make it relevant to each individual's job (bespoke approach), whilst making it practically deliverable and affordable (mass production approach).
- Human resource capacity to engage with and involve communities on an ongoing basis is a challenge for the PCT (this applies to all, not just "hard to reach" community engagement).
- PPI functions have an essentially advisory role, so the responsibility is supposed to lie with policy managers/officers and practitioners.
- The tick box culture, this work needs to be meaningful and not just about ticking a box.
- Disabled and elderly people often don't fit into the definition of "equalities" groups.
- Getting access to the people we want to speak to, especially in the context of People with Learning Difficulties and Learning Disabilities.

"There's a threat of not feeding back to people, people think they raise an issue and making sure that people don't think it's just going into a black hole. It's important that people are fed back to, even if for various

reasons things can't change. I think that's a threat, just making sure we keep on top of that, that we're not disempowering people."

7.0 Influence on policy

The following are comments from interviews in respect of the influence consultations with 'hard to reach' equalities patient groups have had on both NHS Trust and voluntary and community sector action plans and policies.

7.1 NHS Trusts

- Helped to identify or refine the actions we need to take in order to eliminate discrimination and promote equal access to services and jobs.
- Helped to evaluate the effectiveness of the actions we are taking and identify any gaps in these actions.
- Enabled us to check and revise our priorities and actions in our Single Equality Scheme and action plan.
- As a trust, we are appreciating more and more the importance of involving service users from different backgrounds in the design and planning of services.
- Positive response from community groups.
- Building up a reputation as an organisation which is interested in the views and perspectives of a range of stakeholders, including patients from a variety of communities.
- By listening, enabling communities, organisations are getting information in that way, organisations can act immediately either through provision of services, or through commissioning.
- NBT Trust Board has an agenda item for the LINK where questions can be raised.
- Health Trusts appointed Equality and Diversity Managers.
- 'Count Me In' has validated approach and identified gaps.
- Patient and Public Involvement Strategy shaped the way NBT involved patients and is more inclusive.
- Acting immediately on anecdotal feedback.
- Foundation Trust status has an action plan, including consulting with hard to reach groups, influencing how we went forward as a Trust.
- Consultation changed the PALS policy/complaints procedures within the Trust.
- The Maternity and New born services review in 2007, informed the Trust Board.

On developing the South Gloucestershire Carers Strategy.

"The feedback we got from the (BME carers) event is now feeding into our new Carers Strategy, and that will make a difference in terms of the services we commission for carers. On the ground, what people are saying, it does feed into strategy, policies and implementation. Services that we commission and the choices that people have of the services that they want to receive, will add to the range and choice of services."

On the Maternity and New born services review (2007).

"I would say the Maternity review, apart from the standard targets that had to be included to move forward, that the majority of it was directly influenced by what we were told by local people. That has been continued, and their involvement has been continued. In terms of PPI that was a fantastic piece of work. We went to existing groups, we invited people to meetings, there was a whole range, it was left really open, there were telephone conversations, we did some work with some sex workers, with people with HIV, there were lots of confidentiality issues, any which way we could speak to people we did."

7.2 Voluntary and Community Sector

- The issues and concerns that have come out through the engagement work have been fed into the work plans for those working groups to work on.
- Identified gaps in mental health services, breaking down some of the stigma around mental health.
- Increased the number and diversity of participants.
- Working with NHS to ensure people are able to get translations, people can now ring their GP's and ask for translations and they will get it.
- Recommendations from the mental health report will be taken as part of the assessment by the Local Authority on commissioning better and improved mental health services.

8.0 Case Studies

The following case studies are examples in other areas where NHS Trusts have joined together in a partnership approach to consultations with 'hard to reach' equalities patient groups.

8.1 NHS North East takes a partnership approach to deliver an effective Single Equality Scheme

NHS North East has worked together across all of its 23 organisations to develop a single equality scheme framework. A working group from an equality network developed a framework and priorities which have been used by individual trusts to guide local actions. Huge benefits have accrued including avoiding duplication through sharing data, skills and expertise, and undertaking joint consultation and involvement activities.

A performance framework of high level actions has been developed as part of the scheme. This will be monitored across all trusts by NHS North East. Progress on equality data collection is one of the actions and all trusts in the region are encouraged to report on progress on equality issues annually to their Boards. This helps to raise the profile of equality to secure resources for the work. An equality impact assessment toolkit is available for all trusts to use.

The Trust held a conference for staff across the region and commissioned a third sector group to provide feedback from the community on the single equality scheme.

Contact: Chris Rowlands, North East SHA (email) chris.rowlands@northeast.nhs.uk

8.2 Birmingham takes a partnership approach with the 'Be Heard' Consultation Database

'Be Heard' brings together views, comments and opinions collected through public consultation undertaken by Birmingham City Council and all of the organisations making up Be Birmingham.

To visit the database <https://www.birminghambeheard.org.uk>

Be Heard is made up of representatives from the following organisations Cultural, Children and Young People, Environmental, Economic Development, Health and Wellbeing, City Housing, Safer Neighbourhoods, Advantage West Midlands, Birmingham Chamber of Commerce, Birmingham Voluntary Services Council, Job Centre Plus, Learning and Skills Council, Primary Care Trust, West Midlands, onurbation Resilience Forum, West Midlands Police. The Local Authority Chief

Executive, Deputy Leader and Opposition Leader also sit on the Executive Board, as well as a community sector representative. The Government Office for the West Midlands are observers and BRAP (Birmingham Race Action Partnership) act as advisors.)

Contact: Pam Dixon, Consultation Programme Manager
Tel 0121 675 3968 Email pam.dixon@birmingham.gov.uk

8.3 South Birmingham PCT appoint a new GP provider

When South Birmingham PCT needed to appoint a new GP provider, they wanted to get the perspective of patients to ensure they made the best choice. Patients were invited to establish a panel to advise on setting up the new practice. Two representatives of the patients' panel also joined the PCT project team for the appointment of the new provider.

The PPI manager provided them with support throughout the process, from agreeing the service specification to interviewing potential providers and making a recommendation to the PCT board.

The panel received feedback on the tendering process and agreed how it would work with the new provider. Patients were also involved in choosing a suitable new site for the practice.

8.4 'Walkabout' – it's easy to reach the 'hard to reach'

Walkabout is an innovative method of engagement in the form of a half-day walk around an area. Piloted in Bristol and South Gloucestershire at Gypsy and Traveller sites. This is now being developed in North Somerset to visit specified Black & Minority Ethnic (BME) community organisations and/or other 'hard to reach' communities, such as drug & alcohol service user community events.

Contact: Annie Crocker, Gypsy and Traveller Team, Bristol City Council (email) annie.crocker@bristol.gov.uk

Contact: Jay Akerele, NHS North Somerset (email) jay.akerele@nsomerset.nhs.uk

8.5 Reaching Out Linking In

A project to help equalities communities and 'seldom heard' equalities groups to influence policy and service delivery of public bodies more effectively. It is also about improving the support that they get from voluntary sector infrastructure organisations. Although the project works across all equality strands the focus is on work with BME communities; disabled people and groups; and work with vulnerable people living in isolated rural areas. The project operates in South Gloucestershire, B&NES and North Somerset with a part time development worker in each area. The three main delivery partners are CVS South Gloucestershire, DEVELOP (in Bath & North East Somerset) and Voluntary Action North Somerset. There are three specialist advisory partners – Black Development Agency, Community Action and Somerset Racial Equality Council.

Contact: Martin Gregg, CVS South Gloucestershire (email) martin.gregg@cvs-sg.org.uk

9.0 Recommendations

The following recommendations are made to the Sub-Regional Health Community, and to all health service providing organisations working across Bristol and South Gloucestershire, based upon the review of evidence in this report.

9.1 Sub-Regional Health Community

- Development of a Sub-Regional NHS communication and consultation strategy; engaging and consulting 'hard to reach' equalities patient groups.
- Development of a jointly owned community engagement framework for equalities.
- Co-ordination by the Sub-Region of efforts to consult and involve, avoiding consultation fatigue.
- Development of long-term and trusting relationships with communities.

9.2 NHS Trust Boards

- Champions representing each equalities strand at each Trust Board level.

9.3 NHS Trusts

- Directors reporting to the Equalities Committee on what they are doing on equalities.
- Adopt definition BAME – Black, Asian and Minority Ethnic as recommended by the Equality and Human Rights Commission (EHRC)
- GP surgeries having emergency or drop-in appointments available, improving accessibility.

9.4 Information Management

- Development of a cross-border, inter-institutional consultation database for Local Authorities and NHS Trusts, with sophisticated search capacity and requirement to populate.
- Development of one website portal across the local NHS.
- Development of a Social Networking strategy encompassing targeted work of all equalities strands.
- Use new digital media to increase and develop engagement activities.
- Improving communication and information about what's out there, what's available to patients.

- Audit of information available to improve accessibility.

9.5 Training

- Regular Equality & Diversity training for all staff covering all seven equality strands, including basic training around equalities monitoring.
- Culturally aware and sensitive frontline staff.
- Training of statutory sector professionals and clinicians in 'what is the voluntary sector/how to work with it', with added value of partnership working built into wider professional, induction and medical training.

9.6 Voluntary and Community Sector

- Fund reference groups of specific, specialist providers alongside existing Health and Social Care, Older People and Mental Health Networks.
- Establish a Lesbian, Gay, Bisexual and Trans Health and Social Care Network.
- Funding for development work to reach smaller equalities groups.
- Respect the guidance that competitive tendering is not necessarily appropriate for small, local specialist services/support where the 'market' may not warrant competition.

9.7 Communities

- A community development approach to foster and develop Ambassadors and Champions within each equalities community.
- Better use of community radio, particularly reaching out to BAME communities.
- Utilising community events, for example community festivals.
- Consultation and engagement activities on women's health and men's health prioritise across NHS Trusts.
- Consultation and engagement activities with Lesbian, Gay and Bisexual communities prioritised across NHS Trusts.
- Implement (NHS Bristol) 10 LGBT Equality Standards across all health Trusts.
- Consultation and engagement activities with Trans communities is prioritised across NHS Trusts.
- Consultation and engagement activities with communities of Religion and Belief requires further developed across NHS Trusts.
- Support and develop the specialist organisations that give a voice to 'hard to reach' patient groups.
- Co-ordinated outreach approach to engagement and involvement activities with ('hard to reach') communities across the sub-regional health community.

- Planning consultation events at a variety of locations, venues and times to maximise engagement with communities.
- Specialist Health Workers to work with Gypsies and Travellers.
- Specialist School Nurse to work with Gypsy and Traveller children and young people.
- Specialist Midwife working with Gypsies and Travellers.

Appendix – Interview Questions

- 1 Can you tell me about your role and your organisation?
- 2 Can you tell me what consultation exercises have been carried out since 2005 with hard to reach equalities patient groups? How have you and your organisation been involved?
- 3 Can you tell me which initiatives you have undertaken to contact and involve hard to reach equalities patient groups?
- 4 Can you tell me how you feel the outcome of this work has influenced your policies, action plans, department or Trust?
- 5 What would you say are the successes (strengths) of this work?
- 6 How have these successes been measured?
- 7 What would you say the challenges (difficulties, obstacles or weaknesses) of this work have been?
- 8 What opportunities have arisen from this work?
- 9 Can you give examples of delivering to hard to reach equalities patient groups?
- 10 What are the threats in relation to delivering work to hard to reach equalities patient groups?
- 11 Can you identify other examples of best practice in delivering to hard to reach equalities patient groups? Is there anyone else I should be talking to?
- 12 What needs to change to improve accessibility to health services (for patients from hard to reach equalities patient groups)?
- 13 How would you shape services to meet the individual requirements and respect the individuality of patients from a diverse range of backgrounds?
- 14 What actions are you taking to offer personalised health provision in relation to hard to reach equalities patient groups?
- 15 Is there anything that would help you to know in your work that you would like to see included in this project? Do you have anything you wish to add?