

Participation...

Why Bother?

The views of Black and Minority Ethnic mental health service users on participation in the NHS in Bradford

**Report of a community research process undertaken by the
International Centre for Participation Studies,
University of Bradford
and Sharing Voices (Bradford)**

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ICPS WORKING PAPER 2

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1 Introduction

The International Centre for Participation Studies and Sharing Voices Bradford (for information on these organisations, see Appendices 3 and 4) maintain that participation is an important part of a healthy democracy, with benefits for all. However, participation can be anything from empowering to tokenistic, and must be critically examined if we are to understand how to use it effectively. This paper considers the contribution of participation to improved service delivery in the health service.

For beneficiaries, participation can be about ownership and responsibility for the services we use, as well as rights and the chance to express what we want from them. For service providers, participation is widely recognised as an effective way of tailoring services to the needs of the different communities they serve. The NHS and other service providers have made great strides in developing mechanisms for participation by service users. However, these do not always reach all sections of the community. Many individuals feel sceptical about getting involved, unconvinced that their contribution could make a real difference. Through the Participation – Why Bother? workshops, we set out to explore these feelings, to reflect on perceived barriers and identify changes that might help overcome them. The aim was not to look at the substance of service delivery issues, but to try and work out how the process of involving people in decision-making in the NHS could be improved, to make it easier for voices from Black and Minority Ethnic (BME) communities to be heard.

The aims of the project were:

- To find out how BME communities would like to be involved in decision-making processes within the health service, and factors that might be stopping them from being involved, with particular reference to mental health services.
- To facilitate a dialogue between community participants and service providers.
- To help community members think through the value of participation for them.
- To help service providers identify organisational barriers to greater participation.

Participation – Why Bother? involved seven workshops in total. Between February and July 2005 we held five community workshops, followed by a workshop for key health service providers from Bradford District. The series finished with a joint meeting to which both community participants and service providers were invited.

The community workshops looked at contributors' knowledge of existing opportunities for participation in the health service, their views on how they would want to be involved, and practical suggestions for improving participation structures. They were an opportunity for people to think through what it means to participate in the health service, and the value they place on such involvement. They have also generated a snapshot view of contributors' skills and experience relating to participation, and their knowledge and experience of using health services, with a focus on mental health.

The service providers' workshop allowed key staff from three organisations within the NHS in Bradford to reflect on internal barriers to encouraging greater participation, and to hear the findings and recommendations arising from the community process.

The final session allowed all participants to discuss achievable developments within the participation structures, and service providers to demonstrate to members of the BME communities the real value placed on their participation.

2 Research Summary

This summary describes the findings of the Participation – Why Bother? workshops in brief. The rest of the report gives more detail about what we found, and how.

The Community Workshops

The five community workshops involved 63 people, male and female, young and old, from South Asian and African-Caribbean communities.

We asked people for the reasons why they might want to get involved with participation processes in the health service. We found that the main motivation was to do with using experience to create change for the better, and working for community benefit.

The workshops revealed a wealth of skills, knowledge and experience, which service providers could be drawing on to improve services through more effective structures for participation. Participants have a lot to offer, including:

- cultural and community knowledge
- communication and community work skills (seen to be essential in inviting participation)
- a service user's perspective on the health service
- possible solutions for problems experienced.

The community workshops also covered some of the reasons why people don't engage with the health service. The biggest barrier was felt to be the belief that the health service will not listen, and that change won't follow. Participants did not feel valued as a source of solutions, so did not feel encouraged to invest time and energy in engaging. This lack of trust came from feelings that non-medical forms of knowledge are not respected, and from the emotional impact of negative experiences as a patient.

Other barriers included:

- Power structures within the system; a sense of powerlessness can stop people from getting involved. This includes the power of doctors over patients, symbolised by the fact that patients (especially where mental health is concerned) are defined and described by written notes which they have no power to influence themselves).
- Lack of information, making it difficult to have an informed engagement with the system.

Participants also discussed particular opportunities for engagement. In general, it was felt that there are good opportunities for people who are assertive, knowledgeable and confident, but those that are most disempowered by the system may still be excluded.

The community workshops resulted in a number of clear recommendations about how mechanisms for inviting participation could be made more effective. These are listed in the next section of this report. It was felt that the attitude which the NHS brings to participation is more important than the practicalities, important though these are. These should be sensitive, respectful and focused on change.

The Service Providers' Session

The community workshops were followed by a session for key staff from three NHS Trusts in Bradford. It is clear that NHS staff bring both medical knowledge and knowledge of the NHS system and organisations. They were asked to reflect on what their organisations are doing to increase participation from BME communities, identify barriers and think about ways to improve participatory processes. In many ways the views of service providers present accorded with that of community participants, although participating staff did not necessarily feel that their views were representative of the NHS as a whole. There was agreement between community contributors and service providers that the attitudes and approaches of all health service staff are critical to creating change.

The service providers who contributed defined participation as “achieving genuine change” and “handing over some power” – clearly reflecting the views of community contributors. It was felt that there are increasing efforts to engage communities in general, and a growing awareness that more work is needed to engage BME communities in particular, but considerable variation in views on how NHS trusts currently relate to communities in Bradford. Some thought that NHS staff go into communities to listen, while others felt that communities are actually expected to participate on the organisation’s own terms.

The service providers at the session identified many of the same barriers to participation facing BME community members as raised in the community workshops. They also discussed a number of internal barriers which affected the ability of the health service to engage BME communities. These include:

- limited resources for participation
- insufficient understanding of the value of participation from some NHS staff
- national priorities which don’t always allow enough local focus on participation.

The service providers’ session also produced some concrete suggestions for improving participation processes, listed in the following section of this report.

Challenges and Opportunities

The Participation – Why Bother? workshops raised important issues to do with participation itself.

Firstly, there is an issue of power and accountability. In setting up participation processes, service providers need to think about where decisions will actually be taken and by whom, and how the process will deal with tensions and disagreements, for example instances in which communities want to move in different directions to the established thinking in the health service.

Secondly, the culture of the NHS, which is a large service divided up into many different organisations, may itself be at odds with the holistic way in which people think about their health and their experiences. There is a question about how these things can be made to fit together in a way that makes it easy for people to tell their stories, and contribute their experience.

Finally, the NHS could consider how to develop the capacity of its service users to participate. This is to do with their confidence to participate, but also their belief in their own ability to create change within the system. At present, for too many people,

experiences within the health service generate a sense of powerlessness, rather than a sense of their own control and power to contribute to change. If service providers are to take seriously the goal of engaging BME communities, these are critical questions to address.

Conclusions

Participation – Why Bother? ended with a discussion of participation between service users and service providers. This session showed the many shared priorities between community members and engaged and committed NHS staff.

Service providers clearly valued the chance to hear directly from service users, and were keen to have more such opportunities. Community members in particular valued the chance to work collectively on ideas for change. The process as a whole suggested that there is a need for a greater understanding of participation, and the possibilities it offers for positive change, both within the health service and within communities.

Bringing together service providers and service users is a two-way process, involving greater understanding by service providers of the needs of community members, as well as greater understanding by community members of the constraints and limits to participation within the health service.

It is very clear that, as well as the barriers experienced by communities, there are many obstacles for service providers in creating effective participation structures and bringing about change. This is clearly a major issue, and unless it is addressed, it is difficult to see how effective participation processes, trusted by communities to make changes, can be created.

As a result, it is clear that effective participation rests on good communication – listening as well as informing, and honesty and clarity from the NHS about what changes are possible, and how they can be made. In this way service users and service providers can come together bringing their complementary knowledge and experience to the important task of improving health service provision.

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The Participation – Why Bother? project has been a small step in the process of building a local dialogue between service providers and service users in Bradford. The project as a whole has resulted in a series of short-term suggestions, aimed at continuing and building on this work. These suggestions are listed with the community and service provider recommendations.

3 Recommendations

3.1 Community Recommendations

The following recommendations reflect the shared sense of the five community workshops.

- i. Ensure that participation structures are seen to provide possibilities for change:
 - By identifying and demonstrating the ways in which all methods of engagement link to decision-making processes.
 - By creating mechanisms by which senior staff can directly hear the experiences of all communities.
 - By taking a 'whole service' approach to participation, rather than viewing it as the responsibility of specialists within the service – this means training staff to understand and promote the value of patient involvement.
 - By ensuring that involvement is always followed by feedback, so that participants see the outcome of their involvement.
- ii. Demonstrate commitment to change by honestly acknowledging that there are problems at the start of any dialogue (contributors also stressed the value of apologies from service providers where problems had occurred).
- iii. Provide sources of information for participants on alternative means of service provision (service users may not be aware of all possibilities).
- iv. Target particular individuals and organisations using specific invitations to a range of people: service users, carers, families, community based organisations, local activists.
- v. Service providers should go to the community, not vice versa, for example holding a Neighbourhood Forum dedicated to health issues, or events hosted by trusted organisations and networks such as Sharing Voices Bradford.
- vi. Offer a variety of opportunities (formal and informal) for individuals to share their views:
 - Create opportunities for people to participate as a group (this is felt to be less intimidating than being a representative), for example in the format of a workshop to address a particular issue. Service providers should be present, in order to listen and feed participants' views into decision-making processes, but dialogue may need to be mediated through a trusted organisation.
 - Address concerns about service user / service provider power relationships by providing advocacy mechanisms for service users to express their views. Possibilities include: an advocacy group to represent patient interests, employing ex-service users as mentors to help current service users to express themselves, appropriate liaison officers or support workers on wards whose sole role is to hear and represent views.
 - Use mechanisms for communication that already exist, training staff in places where people regularly congregate and feel comfortable (such as places of worship, youth centres and community centres) to act as a

conduit for people's views. This is particularly important in getting the views of people who are experiencing mental health problems but not accessing services, in addition to those of service users.

- Questionnaire to members of BME communities, qualitative rather than quantitative, and followed by feedback on how it was used.
- Employ creative ways of communicating with potential participants – for example through drama.

It is worth noting that, while recognising that some people might want to join formal committees, all the groups focused on alternative models of engagement.

- vii. Advertise opportunities more widely and in a variety of ways:
 - Written information to be available in different languages.
 - Word of mouth, using trusted individuals and mechanisms for communication that already exist. Examples include: voluntary sector network organisations, places of worship, community centres, clinics, day centres, schools.
 - Use local and national Asian magazines and newspapers.
- viii. Use 'partial' translators, including ex-service users, community and voluntary groups. Interpreters who do not take part in the conversation leave participants feeling unsure as to whether the sense of what they say has been got across. A translator who engages in a dialogue, and then translates, inspires more trust.
- ix. Offer practical help in attending, for example providing transport.

3.2 Service Provider Recommendations

- Continue trying to increase the capacity of voluntary organisations and communities of interest, with whom the NHS can work in partnership to access the views of BME communities. The NHS needs dedicated workers to link in with these organisations, and promote different approaches to engagement.
- Monitor who is participating, even within BME communities, to make sure that minorities within minorities are not being missed.
- Prioritise named individuals at all levels (with access to resources) to take responsibility for promoting participation.
- Set small, achievable, realistic goals in relation to participation, to build credibility (this means saying no as well as yes, when engaging in dialogue).
- Work towards more internal communication between organisations within the NHS, encouraging participation as if the health service is a single organisation.
- Training for all staff to promote greater cultural awareness and the confidence to listen to patients' views.
- Recruit more BME staff.
- National policy needs to enable local organisations to focus on BME issues.

3.3 Participation – Why Bother? Recommendations

The above recommendations together offer comprehensive suggestions for how the health service could better engage BME communities in participatory processes. However, some of them may be long term changes, with organisational and resource implications to consider.

The following recommendations are short term measures which are seen to arise directly from the findings and process of the Participation – Why Bother? project.

- Build on shared priorities indicated by this process, by initiating work on the community recommendations, in particular the three chosen as short-term, medium-term and long-term goals by the joint meeting (see Appendix 1).
- Build on good will and commitment shown in this process by community members by ensuring feedback of subsequent work and progress. This information can be shared through Sharing Voices (Bradford).
- Within work on promoting participation, develop opportunities for NHS staff and communities to think about participation, in order to increase understanding of its value and purpose, both within the NHS and within communities. This can be achieved through training and discussion internally, and with communities through clarity of purpose and honesty about possibilities for - and limitations to - change as part of the participation process (see section 6 of this report).
- Provide opportunities for NHS staff to discuss problems and solutions directly with service users.
- Consider how participation processes can be linked to means for change, in ways that are very clear to communities. In the same way, limitations to change must be made equally clear, in order to avoid disillusionment.
- Learn from organisations with the experience and capacity to support a service user / service provider dialogue, and consider how this work can be resourced and continued.
- Consider how the approach of the Participation – Why Bother? process to engaging communities (group community meetings hosted by trusted organisations, followed by a facilitated joint session with health service staff) could be used within health service participation structures.

4 Methodology

4.1 Community workshops

63 individuals attended the community workshops. Of these, 25 were women and 38 men, 10 were African-Caribbean and 53 South Asian.¹ While many were mental health service users themselves, others had experience of mental health issues as carers, friends or family members of people experiencing mental distress.

Community workshops were held with the following groups:

- Elderly South Asian women
- Men from BME communities
- African-Caribbean women
- South Asian women (25-60)
- Young people from BME communities

The workshops were arranged in this way to create a safe and comfortable atmosphere, where individuals could speak freely about their experiences and views. This also allowed for gender and ethnicity as factors in how people engage with the NHS. Sessions were facilitated by up to four staff from ICPS and SV(B).

Contributors were recruited by inviting members of Sharing Voices support groups, and through other community organisations and centres working with BME communities in Bradford. Sharing Voices staff engaged a key member of staff in each of these organisations to identify individuals who might be interested in participating. Sharing Voices' networks of trust and personal relationships – both with individual contributors and with staff in organisations trusted by potential contributors – were essential in getting people interested in the workshops.

All sessions were held at the Sharing Voices' premises, a venue known to participants, except the young people's session, which was held at a youth centre. Sessions were 2-2.5 hours long, followed by a meal provided for contributors. People were in most cases offered transport to the venue. This was particularly important in terms of involving elderly people. Transport was not offered to the young people's session, as in this case facilitators went to their venue. With the exception of the session for elderly South Asian women, workshops were conducted primarily in English. Facilitators with the necessary language skills were present. While understanding English, the elderly South Asian women chose to speak in Punjabi, allowing them to express sensitive or complex ideas more fluently. Contributions were recorded by facilitators on flipchart paper, in sight of everyone present, with a non-participating note-taker present at each workshop to take detailed notes on the discussion. In addition, facilitators met immediately afterwards to discuss the session.

¹ Individuals who attended the community workshops are referred to as contributors in this report, to distinguish them from 'participants' in terms of the NHS more generally.

4.2 Service Providers' Workshop

8 participants attended the service providers' session, from Bradford and District Care Trust, South and West PCT and City tPCT. Participants were made up of senior staff and those with particular responsibility for either participation or mental health. Attendance across the organisations varied. In each organisation, a key person working on participation was asked to help engage other members of staff with the Participation – Why Bother? process.

4.3 Joint Meeting

9 service providers and 12 community members attended the joint meeting. Service providers were asked not to attend unless they were able to attend both meetings. It was felt that attending the first meeting was an essential precursor for the joint meeting, as all participants should have had the opportunity to reflect on the issues affecting their community or organisation prior to engaging in a shared conversation. Attending the joint meeting was felt to be essential in demonstrating commitment to the community members who attended. The joint session was facilitated by a mixed group of health service staff, and ICPS and SV(B) staff and volunteers. At the end of this session, all participants were asked to evaluate the process as a whole.

4.4 Methodological issues

Through this project, we created an opportunity for mental health service users within BME communities to share their views and experiences of participation with health service providers. The workshops have been designed to offer contributors space to reflect on the value of participation to them, and to help them identify the skills and experience that they have to offer. As a result, the workshops followed a fluid agenda, allowing flexibility for contributors to lead the discussion.

In this way, the workshops contribute to the active promotion of participation within Bradford's BME communities, as well as providing evidence for the development of participation structures within the health service. Contributors' positive response to the community workshops rested in large part on the expectation that their views would be heard and engaged with by health professionals.

Each stage of the process served an important purpose within the project as a whole. The community workshops allowed service users to explore sensitive issues in a neutral environment; the absence of service providers freed them from perceived and actual power dynamics between service users and providers. The service providers' session was intended to allow a confidential assessment of participants' recommendations, in particular to facilitate discussion of creative possibilities without a fear of raising unrealistic expectations. Finally, a joint session was felt to be crucial both to ensuring that community participants feel that they have been heard by service providers, and in generating jointly agreed forward plans.

5 Findings

One of the most striking things about the process was the extent to which each community workshop generated similar findings. The following is a summary of the broad sense of all five workshops, and as such expresses the views of community members contributing to the Participation – Why Bother? process. Each point was not necessarily shared by all contributors, but there was a shared strength of feeling behind each point represented here. Quotes are drawn from all workshops, though they are specific to a particular group, this is indicated.²

5.1 Motivations

There was an overwhelming willingness from contributors to engage with issues of mental health care, to contribute to dialogue with service providers and to be heard by them. This is not unique to participation within the health service, but felt to be indicative of a huge willingness within the community “to advocate at any level.” Motivations were largely bound up with the idea of creating change for the better through participation, but contributors also understood that participation could benefit the participants, in terms of empowerment, increased understanding, and through the act of being valued – “to be talked to with love and respect is a cure in itself.”³ There was a clear sense that service users can use their experience to make a real difference to service provision. Understanding these motivations should help service providers develop opportunities for people to get involved. The following summarises the main motivations expressed by our contributors:

- To “use our experience of mental health problems and the NHS to help others”
- An understanding that there is “increased power to make a difference if people come together and act collectively”
- To “see if we can improve the NHS”
- To “understand ... the difficulties that mental health service users face”
- To “feel enabled instead of pitied”
- To help BME communities engage “in ways that benefit the community”
- Religious duty to help others – “through giving you gain God”⁴

5.2 Skills, Knowledge and Experience

The desire to engage with processes of improving mental health care is based on a clear, if sometimes unstated, understanding that community members have a lot to offer the NHS. The workshops demonstrated a wealth of skills, knowledge and experience, which service providers could be drawing on to meet broader NHS goals, through effective structures for participation.

5.2.1 Cultural and community knowledge

As these findings series make clear, all our contributors have a wide knowledge of cultural norms and community structures, which they bring to bear on their experience of the health service. Those from South Asian communities in particular also have the necessary language skills for working within diverse communities in Bradford.

² Not all points are supported by direct quotes, as workshops were not tape-recorded. These findings are drawn from detailed written records of the workshops.

³ Quote from the elderly South Asian women’s workshop.

⁴ Quote from the elderly South Asian women’s workshop.

Contributors felt that this broad base of knowledge and skills is particularly relevant to the field of mental health in the following ways:

- Understanding of the impact of mental distress (and mental health services) on the family as a whole, and conversely understanding the family and community context against which mental distress occurs – in total a holistic understanding of mental distress and support for mental distress.
- Understanding community views of mental distress and mental health services, for example, recognising the widespread perception that psychiatrists will make things worse, cause more stress.
- Expertise as carers, service users, and providers of support (to friends, family and neighbours).

5.2.2 Communication and community work skills

Our contributors shared an understanding that inviting participation is community work, and that it draws on the same skills. There is a strong sense that organisations inviting participation need to recognise this, and to make the investment of time and resources that good community development work requires.

These are some of the skills and opportunities described by our contributors:

- Vast experience of community work, including advocacy, mentoring, coaching, fundraising, admin and committee skills and one-to-one support
- Listening and communication skills, the ability to be non-judgemental, validating and accepting (women's groups particularly emphasised the importance of these skills)
- Skills in alternative forms of self-expression, such as art, creative expression, and music, allowing people's voices to be heard in ways that they feel comfortable with
- Experience of challenging racism in diverse settings
- Formal and informal networks – seen to be essential for achieving anything in the community. These include schools, youth and mentoring projects, religious organisations, and community projects. They are seen to be an opportunity for two-way dialogue, useful both for informing people and in gathering views.

5.2.3 Knowledge of the health service

The Participation: Why Bother? workshops focused on participation in the health service, rather than specific service provision issues. However, the discussions did demonstrate the extent of thinking, experience and reflection on these issues that service users and communities could bring to participation processes.

Contributors referred to the following positive experiences. These were expressed as isolated examples within more general structural concerns:

- Individual staff who treat you with humanity, trust and respect
- Finding a GP who advised other forms of support such as self-help groups instead of anti-depressants
- Day Centres were felt to be helpful as places where people can talk together, seek help and get information
- The quality of children's services
- Practical changes in provision, such as Halal food and prayer rooms
- Increasingly diverse staff

The major problem identified in the area of mental health care, across all the community workshops, was that of inadequate follow up care and support. There is a clear sense that mental health services are a system of crisis management. The features of this are seen to include:

- The overuse of drugs as sole treatment, instead of time to talk.
- Inappropriate referrals to support groups – contributors observed that patients are referred to support groups without time being spent identifying the particular needs and wishes of the individual.
- Lack of information to patients about where to access ongoing support.
- Long waiting lists for essential services such as counsellors.
- Wide experience that the voluntary sector has to ‘pick up the pieces’ afterwards.
- Discharging people without knowing what support they are going to get at home.
- A failure to look at the whole person. One contributor gave the example of a person being prescribed pills for depression which stopped them from driving, with the result of actually increasing their isolation.
- A narrow interpretation of mental distress that does not attend to its social impact, resulting in short-term, medical solutions, rather than longer term, holistic ones.

Contributors also repeatedly raised the point that GPs have insufficient time to spend with individual patients, with the result that specific circumstances and particular needs are not taken into account. This lack of time is seen to be especially a problem in the field of mental health, where people need time to express themselves. This lack of time is seen to lead to inappropriate diagnoses, and a tendency to treat physical symptoms instead of identifying underlying causes.

Contributors also raised concerns specifically to do with their treatment as members of ethnic minorities. These concerns were mostly seen to be a fault of the system, rather than individual members of staff.

- Lack of culturally appropriate treatment. One contributor was offended to have been asked, as an older Muslim woman, if she drank alcohol. This was seen to be a problem of the system rather than the individual doctor, as the GP was himself Asian, and assumed therefore to have the necessary cultural knowledge.
- A strong sense from some that psychiatry does not take account of spiritual beliefs, leading to treatment viewed as inappropriate, such as enforced hospitalisation where the individual might respond more to a spiritual healer. Contributors understood that this would mean a significant shift for the system as it stands, but felt that treatment needs to be appropriate to individual belief if it's going to be effective, especially in relation to mental health.⁵
- The provision of services is not informed by an understanding of the communities the services are for. For example, there are high levels of stigma attached to using mental health services and being labelled as having a mental illness (many people won't marry into a family that they know has accessed MH services). What is significant is that this stigma is attached to using services and being labelled, rather than actually to the fact of experiencing mental distress itself.
- The African-Caribbean women's workshop raised the issue of inappropriate diagnoses of schizophrenia as a particular concern in their community.
- There is a lack of translators; patients have to rely on family members and other patients.

⁵ The relationship of religion to mental health is of course contentious, and was debated by some of our contributors. However, this indicates some of the discussions that could engage communities in exploring improved mental health service delivery.

In some cases, problems do result from an individual lack of cultural knowledge, or from individual prejudice:

- Lack of knowledge particularly about minority faiths, such as the Rastafarian faith.
- When African-Caribbeans are “loud and expressive,”⁶ this may be reacted to as aggression, making it harder for people to voice their concerns, particularly in stressful situations.
- Experiences of racism and prejudice. Contributors gave examples of staff assuming that women wearing a headscarf would not be able to speak English, negative reactions to Islamic dress, and Asian women receiving less attention than White women on the same ward (as a result women in hospital provide support to one another, even though they are in need of support themselves).

5.2.4 Possible Solutions

The range of experiences described above means that service users such as our contributors are well-placed to offer thoughts on possible solutions. Ideas raised in the community workshops include:

- Attending to socio-economic factors that impact on mental distress, for example isolation.
- Showing respect for individual identities by offering people a choice of how they want to be helped. This could include counselling, alternative therapies and local service providers, as well as medication.
- Ensuring that people know where to access support early enough, by involving more grassroots community organisations. This is seen to have the additional benefit of challenging stigma and informing the community about mental health, without the problematic use of labels associated with mental health service provision.
- Providing for greater levels of interpersonal support, through:
 - o Peer support through mentoring schemes, self-help groups and mechanisms to support informal advocacy by friends and relatives (where it is wanted by the service user).
 - o Drawing on ex-service users and community members for appropriate and skilled ongoing support.
 - o Support groups with a purpose beyond mental health, again allowing for peer support without ‘labelling’, for example fitness and exercise groups (endorphins being recognised as a natural anti-depressant).
 - o Working with whole families (again, with permission of individual service users), to increase understanding and support.
- Using the wealth of cultural research available in providing training and written information for all staff, as well as actively seeking to employ people who have this knowledge.

5.3 Barriers to participation

Overwhelmingly, the main barrier to participation is a lack of trust that people will be listened to or that change will follow. Years of negative experiences have a significant emotional impact, which results in this lack of trust. The system is not seen to be self-critical: “one size fits all, and if it doesn’t fit you, it’s your fault.”⁷

⁶ Quote from African-Caribbean women’s workshop.

⁷ Quote from African-Caribbean women’s workshop.

As we have seen, the main motivation for participation is to help create change for the better. If patients do not feel respected as a source of solutions and improvements – and they clearly do not – then engaging with the system does not feel like a good investment of their time and energy. They do not engage because they do not believe that the changes they want to see will follow.

While this lack of trust is the main barrier, there are others, to do with power, information and difficulties with existing systems for participation.

5.3.1 Lack of trust

The majority of contributors felt that their experiences in individual care have not led them to believe that the system as a whole is listening. Experiences identified as leading to this lack of trust include:

- Widespread experience that other (non-medical) forms of knowledge are not valued or respected, which is experienced as a patronising (even arrogant) assumption that patients don't know or understand what is happening. This is experienced especially strongly in the field of mental health, where service users feel that little value is placed on their word or their understanding.
- Unanswered questions, when patients have tried to engage with staff.
- Practices are seen to develop to suit professional convenience, rather than to meet patient needs, with patients feeling that they are an inconvenience rather than a customer or a citizen.
- Contributors who had tried to raise concerns reported being treated with a lack of respect and empathy.
- The feeling of being at the bottom of the hierarchy, in particular experiencing difficulties in getting to talk to their consultant
- Lack of time spent by doctors, meaning that patients do not feel important or valued. Contributors expressed strong feelings of not being heard.

Other factors relating to this lack of trust apply specifically to BME communities:

- The feeling that BME communities have been neglected, and that services do not meet their needs.
- Concerns about wider issues of institutional racism, arising from particular experiences of racism (already discussed).

The impact that these experiences have on service users' willingness to participate clearly demonstrates that participation cannot be seen as separate to or distinct from the working of the system as a whole.

5.3.2 Power

Contributors were very conscious of the power structures within the system, and their own relative powerlessness. Participation requires a belief in your own power to create change. When people feel powerless they do not think that it is worth getting involved.

The power of doctors over patients is a major factor. Contributors understood that long-term mental health service users fear judgement and negative repercussions in terms of care if they were to express their concerns.

Contributors were strongly affected by the powerlessness of service users in relation to their written notes, which in general they do not see, and which they have no influence over. This was a very emotional subject, which arose repeatedly, and one

which undoubtedly affects service users' understanding of their own power within the system. There is a clear understanding that you are labelled by what a doctor writes about you, that you have no right of redress, and that this stays with you forever, carrying more weight than any subsequent events or experiences. The stigma of this is believed to affect subsequent treatment, even if it is for an unrelated complaint.

More simply, the very act of being labelled leads to a feeling of powerlessness, a lack of control over how you choose to present yourself, about what your identity is. This sense of powerlessness is compounded where service users have experienced force and violence in mental health care. In the words of one contributor: "the system takes away your confidence to contribute to change." The Elderly South Asian women's group saw a still more direct impact from this sense of powerlessness: "if you have suffered from a system, it is harder to speak out against it."

These power dynamics are seen to be built into mental health services based on the supremacy of psychiatric knowledge. In hospitals, service users often see a succession of doctors. This makes it even harder to feel in control of your own care, having to repeat personal histories and views without the time that is needed to build a trusting relationship. Contributors felt that it is easier for doctors to act in a way that disempowers the patient because they see them only when they are in hospital. An ongoing relationship would change the power dynamics, and ensure greater accountability.

The NHS itself is seen as a hierarchical system, which makes it hard to challenge senior staff, whether in relation to your own care or in raising a general concern. Contributors also raised the issue of wider power structures, for example the sense that power lies with pharmaceutical companies much more than with patients.

5.3.3 Lack of information

Contributors felt that they are not given enough information to engage with choices even about their own care. This means that it is difficult to challenge decisions or to make informed choices. Mental health service users amongst the contributors felt that they are not given sufficient information about the reasons for their treatment. There was also a widespread concern about a culture of 'gate-keeping' information, in particular by receptionists.

5.3.4 System difficulties

The opportunities for participation that are currently on offer present their own set of barriers, as well as opportunities. These are looked at in more detail in the next section.

5.4 Existing NHS mechanisms for participation

5.4.1 Lack of knowledge

There was a general sense that most people do not know who to turn to or where to go to engage with issues of concern to them about the health service. Though a small number of contributors knew about one or other of the mechanisms listed below, most were completely unaware of any spaces where the views they want to express are invited, or would be listened to. Many were not aware of any way in which they could give feedback to the NHS. The group of Elderly South Asian women said that they had

never tried to tell their stories to the NHS before, because all interactions with the NHS involve talking one to one with someone, and that person is always asking the questions. They were clearly willing to talk, but did not know where to go.

5.4.2 General concerns

As discussed above, some contributors doubt whether there is a genuine commitment to change; getting involved is seen to take a lot of effort and energy for very uncertain results. There is a widespread perception that what is on offer (discussed in more detail below) is 'lip-service' or tokenism.

Contributors felt that there are good opportunities for people who are assertive, knowledgeable and confident, but those that are most disempowered by the system are still excluded. There is concern that power dynamics such as gender are not addressed, and that opportunities are not accessible, with too much emphasis on written communication, and issues around the use of technical language – seen by some as a means of telling people how to talk about their experiences.

5.4.3 Views on specific opportunities

The opportunities discussed below do not give a complete picture of opportunities for participation in the health service available in Bradford. However, these are the ones that contributors knew about and commented on.⁸

Patient and Public Involvement (PPI) Forums

The vast majority of contributors did not know about PPI Forums, or any other public or service user committees. However, when describing the ways in which they would like to contribute their views, they did not immediately think of forums and committees. In particular, there was a sense that many people would not have the confidence to contribute in this way. One contributor did get information about joining a PPI Forum, but felt that there were too many hoops to jump through, and was put off by the selection process, feeling that the NHS shouldn't choose who is on the forums.

Support Workers

A number of contributors had come across support workers on wards, whose role they understood to be to feedback their views on services. This was very much welcomed, and felt to be a safe and appropriate way in which to engage.

The only concern expressed about support workers was a fear that they are not taken seriously by other staff.

Consultation

Some contributors were aware of service user questionnaires. One woman had filled one in, but was put off from doing it again. This was because she got no follow-up on her contribution, and because she felt that her views were expressed inaccurately by the closed, numerical style of the questionnaire. In general, contributors felt there was a place for questionnaires, but that these should be open-ended, with space for people to express their own views.

⁸ Other opportunities include the voluntary sector User Carer Link Project, which focuses specifically on getting user and carer views, the Bradford and District Care Trust User Monitoring Group, and the Mental Health Forum, an open forum for the discussion of issues around mental health services.

Patient Advisory Liaison Service (PALS)

Contributors who were familiar with PALS were positive about the availability of information through this service. However, there were two main concerns: firstly, that officers don't have power to effect changes, and secondly, that it operates in a very functional way, as a go-between, when empathy and advocacy are needed.

In general, complaints procedures are felt to be too complicated, particularly for people who do not have English as a first language. Some contributors had tried to use the complaints system, but were disillusioned because they did not see any results.

5.5 How people would like to be involved

Contributors showed a clear willingness to engage with the NHS in a number of different ways, ranging from wanting to take a more active role in making personal choices, to involvement with decision-making processes.

In particular, contributors had a sense of their own potential, as service users, carers, neighbours, friends and family, to directly support others going through similar experiences. They saw opportunities for people to be directly involved, as well as contributing to decision-making processes. They saw that service users need support to help them speak, that this must be an ongoing process, an investment of time to build trust. Similarly, people need a choice of who they want to talk to. Staff or support workers from the same community should be available, but it should not be assumed that this is what is wanted (assigning Black patients to Black staff can provide an excuse for other staff not to engage).

The most important message coming through the workshops was about the attitude that the NHS must bring to inviting participation, rather than the practicalities. Contributors want professionals to acknowledge the importance of the subject matter to the participants – “people’s lives in your hands”⁹ – and develop ways of involving people that are sensitive to this, respecting all views and experiences and acknowledging that the experience of a person is the truth for them. Equally, participation must be seen to relate to change, if people are going to feel it worth getting involved. Direct dialogue with providers is seen to be very important.

The practicalities of how people want to get involved are covered in more detail in the recommendations. However, there were two strong messages that should be mentioned here. Firstly, that there should be opportunities for people to engage through a group process, not only as individuals. Secondly, that it may be inappropriate, or at least daunting, for individuals to act as representatives. There was a strong sense that what is needed is to help people have the confidence to speak for themselves, and provide appropriate spaces for them to do so, rather than focusing on a few people who are assumed to speak for the majority.

Contributors felt that much could be learned from community organisations such as Sharing Voices Bradford, which is very effectively engaging with BME communities, by tapping into cultural, religious and personal knowledge.

⁹ Quote from South Asian women’s workshop (25-60)

5.6 Service Providers' Perspectives

It is well-understood that NHS staff are able to bring in-depth medical knowledge to the shared process of improving health service provision, as well as extensive experience of the workings of the NHS system and organisations.

The service providers' workshop allowed interested representatives from the three participating trusts to reflect on what their organisations are doing to increase participation from BME communities, identify barriers and creative ways forwards.

In many ways the views of service providers present accorded with that of community participants. However, it is worth noting that when asked if their views were representative, the consensus was broadly that they were not. It is perhaps inevitable that those service providers who get involved in initiatives such as this will be those who have already done most thinking about the issues, reflected in the clear understanding from those present (as well as from community contributors) that the attitudes and approaches of all health service staff are critical to creating change.

5.6.1 Definitions

Participants in the service providers' session defined participation in the following ways:

“achieving genuine change” “improve services” “sharing responsibility”
“challenging the ‘norm’” “gaining a different perspective” “‘handing’ over
some power” “‘putting’ people at the centre of their lives (acknowledging that
they are at the centre of their lives....)” “partnerships / working together”
“sharing knowledge / skills / experience” “two-way process”

Overall, these definitions clearly agree with the importance given by community contributors to effecting change, and shifts in decision-making power.

5.6.2 What's on offer in terms of engaging BME communities

The service providers in the workshop all represented NHS Trusts. There was some discussion about who should have responsibility for encouraging or inviting participation, with a sense that it was not necessarily the role of the trusts, rather that of Commissioners or PALS officers.

Children's services were singled out as being particularly good at communication. Initiatives include working in partnership with other agencies, working with carers and families, dedicated participation workers. However, even in this area, it was felt that more could be done to engage BME groups. One participant observed that community and voluntary sector groups are doing better in this regard than statutory organisations. The community findings, while not demonstrating an awareness of these specific initiatives, agreed that there is good communication with parents about the individual care of their children.

Trusts are also supporting community and voluntary sector organisations such as Sharing Voices (Bradford). The service providers present saw this as immensely valuable, but were aware of the danger of NHS organisations feeling absolved of their own responsibilities as a result of funding other work.

5.6.3 Measuring success (participants' assessment of their organisations)

The service providers were asked to assess their own organisations' success in involving BME communities in health service participation processes. They were asked how good they thought the organisations were in the following areas:

- Consultation
- Giving information
- Giving feedback
- Engaging people in their own care
- Engaging people in decision-making processes
- Engaging the community and voluntary sector

Most felt that their organisations performed around the middle of the range in all areas. 'Engaging people in their own care' and 'consultation' were rated a little higher than others, and 'giving feedback' 'engaging people in decision-making processes' and 'engaging the community and voluntary sector' were rated a little worse. On the whole, there was a sense that their organisations were getting better at consultation, but not making as much progress in terms of more active participation in decision-making processes.

There was also considerable variation in views on how NHS Trusts relate to communities in Bradford, from the view that they go into communities to listen, to the view that they try to control the agenda and expect people to participate on the organisation's own terms.

Participants felt that efforts to involve BME communities in participation processes could be seen to be working if:

- Services delivery became "more culturally appropriate."
- Use of services reflected diversity of population.
- "Positive feedback from service users."
- Health organisations became "more able to change and be flexible."
- BME communities are using PALS, and reporting complaints.
- Workforce becomes representative of communities.
- Responsibility is taken by communities to get involved.

It was pointed out that encouraging participation is a continuous process; there isn't a point at which you have 'succeeded.'

5.6.4 Barriers to participation

Participants in the service providers' workshops identified a number of barriers to participation that they believed faced members of BME communities.

- Rigid and formal mechanisms for participation, which are not culturally sympathetic.
- The 'territorial' nature of the NHS – many small organisations working within the health service, who perhaps do not always work holistically. The way that all these organisations work within the NHS is also not always made sufficiently clear to service users, which makes it hard to engage.

- The services themselves are across the board not sufficiently welcoming to BME communities, including lack of language provision, euro-centric definitions of mental health, unrepresentative staffing, and a lack of cultural understanding or training for staff. Members of BME communities are therefore less likely to feel welcome to engage with the health service to make it better.
- A sense of powerlessness, including the fear that if you complain while still in receipt of services, this will impact badly on your care.

Participants also were aware of some internal barriers, stopping the health service from developing the ability of service users and communities to participate:

- Limited resources for inviting participation (reflecting the fact that participation could be higher on the organisations' priorities). This includes a lack of staff time to listen to patients' views.
- The fact that not all staff recognise the value of or need for participation from service users and communities. This was described as the 'McDonalds approach'! – only one thing on offer no matter where you are, and “if it's good enough for us, isn't it good enough for them” – “a culture change is needed to change hearts and minds across the NHS.”¹⁰
- Competing national priorities, which don't always allow local organisations to focus enough on participation, or to respond to local agendas expressed through participation.

5.6.5 What's needed

The service provider session resulted in a number of recommendations for improving participation, many of which clearly echo the recommendations arising from the community workshops, in particular a recognition that change needs to happen within the NHS, both in terms of staff attitudes to inviting participation and in developing more open and flexible structures for service users to share their views.

¹⁰ Quotes from participating health service staff.

6 Challenges and opportunities

As well as producing clear and concrete suggestions for ways to improve participatory processes, the Participation – Why Bother? workshops raised important issues to do with participation itself. If service providers are to take seriously the goal of engaging BME communities in participatory processes, then these are critical questions to consider. This section looks at three issues: power and accountability, the existing organisational cultures of the NHS, and the capacity of individuals to participate.

6.1 Power and Accountability

The findings demonstrate very clearly that some people do want to get involved if they believe that change will result from their efforts. In one sense, this should not be problematic. The key purpose of Patient and Public Involvement, as defined by the Department of Health and the Commission for Patient and Public Involvement,¹¹ is to improve the quality of NHS services, make recommendations for improvements and raise standards. Therefore the goal of change is built into these systems of participation. Where change happens, it is essential that participants receive good feedback, if they are to value and continue their participation.

However, it is also clear that organisational agendas exist around the extent and direction of change. The Department of Health believes that PPI Forums will rarely need to adopt an adversarial approach, and expects that participants will adopt a positive and collaborative approach.¹² While this is undoubtedly desirable, it may mask potential difference and conflict. Service providers need to think through the boundaries to participation, and the ways in which difference and conflicting views would be handled, if participation is to be meaningful. Failure to do this risks participants and communities becoming disillusioned when they do not see the changes they had hoped for.

For example, the men's community workshop raised the issue that mental health problems are commonly culturally understood to be the result of a 'curse'. This is clearly a contentious issue, and not all contributors shared this view. However, for those that did, it placed an emphasis on spiritual healers. Some wanted the choice to access this type of treatment recognised by mainstream mental health services. This type of cultural divide raises fundamental questions about the participatory process:

- ❖ What mechanisms are there for participants to initiate changes that the dominant culture finds challenging?
- ❖ To what extent is the health service trying to meet the needs of communities as expressed by the communities themselves, and to what extent is it trying to engage communities with what it understands to be its goals?
- ❖ How do we create effective mechanisms for participation that balance the needs of people with different beliefs – across and within communities?

¹¹ *Patient and Public Involvement Forums: the Department's View and The Key Principles of Patient and Public Involvement*, CPPIH, 2004.

¹² *Patient and Public Involvement Forums: the Department's View*, 2004, CPPIH.

There are no easy answers to these questions, but attempts to invite participation are unlikely to meet the expectations of diverse communities unless they are addressed. One implication is that service providers need to be clear and open about the extent to which decision-making power can shift to participatory structures, and up-front about both the possibilities for change and the limitations to participants' influence.

6.2 NHS Organisational Culture

In thinking about participation, large organisations need to consider how their organisational culture, the way they work and get things done, affects people's ability to get involved. This may include structures and procedures that are taken for granted by those within the organisation, but which those outside find difficult or off-putting. Our experience in the community workshops suggested at least two areas in which this seems to be the case.

- People experience health and ill-health in a holistic way. In the community workshops, contributions ranged fluidly across physical and mental health and services, or across making active choices relating to individual care, challenging decisions or events, and expressing views on the system as a whole. By contrast, in the service providers' session, there was much discussion over which organisation was responsible for implementing initiatives around participation. There is clearly a tension between the necessary divisions within an organisation the size of the NHS, and the ways in which people present their experience and knowledge ('telling their stories').
- Similarly, there is a tension between the implementation oriented organisational culture of the NHS – with a focus on tasks and delivery – and the narrative orientation of people who are speaking from their personal stories and journeys.

It may be that these things present challenges in terms of relating the views of those who have valuable experience of service provision in the most effective way. However, building a system for participation that starts from the ways people talk about their needs and experiences, rather than one framed by service providers, may also provide creative opportunities. The NHS will draw on a much broader range of people, views and experiences through such an approach, as opposed to a more formalised system of participation. The challenge for service providers in designing effective opportunities for participation is to identify the means by which these powerful voices can be translated into change.

6.3 Capacity

The workshop findings demonstrate that the capacity to participate depends on much more than confidence, knowledge and understanding how to get involved, important though these things are. In the light of the findings, an effective system of participation clearly rests on supporting individuals' sense of their own power to create change within the system. In inviting participation, service providers need to consider how this can be done. It links to the broader issue of trust in the system, but it also relates to the individuals' experience of being in control of their own care. The NHS has extensive contact with its client group; service providers could make a choice to nurture active participants through all contact with service users. A holistic approach to participation would develop and build on the sense of control and value that a patient experiences in actively making choices about their own care, in order to develop a culture and capacity for broader participation in the NHS.

7 Conclusions

The final event of the Participation – Why Bother? project was a joint meeting to which both community participants and service providers' were invited. Together, they considered the recommendations arising from the community workshops, prioritised them, and began discussing timescales and methods for implementation.

As well as benefiting participants through shared discussion, this session (and comments from participants afterwards) was very helpful in thinking about the nature of community participation in the health service.

The process of prioritising short-term and long-term goals in relation to improving participation demonstrated something that was evident throughout this project, the similarity of priorities between engaged and committed community members and NHS staff. While there may be other competing priorities, both within communities and within health service organisations, there is clearly a great deal of shared ground on which to move forwards towards more effective processes of inviting participation, with the aim of improving service delivery.

Community members in particular valued the opportunity to work collectively on ideas for change. This, if built into NHS decision-making processes, has the potential to turn a sense of problems and powerlessness into empowerment. Equally, staff valued the time spent discussing experiences and possibilities with service users. It became evident that service providers spend a lot of time working on change together, and that they found the opportunity to work directly with service users themselves powerful and important, and perhaps too rare. Comments from the evaluation of this session suggested that service providers were more keen to hear from community members than the other way around – and that community members were on the whole more hopeful that change would follow from their being heard. This suggests not that there is no communication between service providers and service users, but that it is overwhelmingly one way only – and also that service users are more urgently focused on the need for change. Processes of participation clearly have to address both these issues in order for all participants to see their value, and stay committed.

There was however a clear sense, both in the final session and throughout the process, that many participants, service providers as well as community members, were surprised at the breadth and complexity of the issue of participation, suggesting a need for the health service to build in more training and preparation in its work to promote and invite participation. For example, it seemed to be easier for health service staff to focus on the issue of improving participation when discussing it jointly with community members. In the service providers' workshop there was some tendency from some participants to focus on how to improve services *for* BME communities, as distinct from talking about how to better engage and hear *from* BME communities themselves, demonstrating the levels of commitment to improved services, but perhaps also indicating the need for a greater profile for participation itself within the health service.

The final session also demonstrated a very real barrier to creating meaningful processes for participation, which needs to be addressed as part of taking seriously the aim of involving communities in the health service.

It was very clear that NHS staff, though themselves committed to the goal of increasing BME participation in the health service (and thereby improving services), found it extremely difficult to imagine routes to actually making changes. There was a sense of the individual's own perceived powerlessness within the whole organisation, almost regardless of the seniority of the individual. One example is the contrast between service providers' willingness to accept that acknowledging problems is a short term change, and the difficulties they expressed in seeing how this could actually be implemented in the short-term (see Appendix 2). This sense was supported by an awareness that change is difficult to achieve because the NHS is not one organisation. This creates problems in terms of knowing how and by whom changes can be made, and in ensuring consistency across the health service as a whole.

This is not to suggest that service providers are being unrealistic in this pessimistic assessment of the possibilities for change (though it may sometimes be possible that someone from outside the organisation can help people think differently about particular issues). It is however a real problem if participation structures do not (or not seen to) result in actual change, given that change is understandably the overwhelming motivation for engagement, as demonstrated through the community workshops. While it may not be easy to address, any real or serious effort to engage communities must take account of this issue.

This needs to be a two-way process. Communities need to understand the complexities of each issue, the barriers to creating change alongside the possibilities. However, it is clear that this is only a realistic expectation of communities where the NHS makes transparent the whole decision-making process, is honest about difficulties as well as successes, and engages people in a dialogue about solutions, rather than simply asking them for information about their experiences.

Change obviously cannot happen overnight, either in terms of the issues that BME communities raise about the health service itself, or in terms of how the health service tries to involve people from all communities in dialogue and decision-making.

Participation – Why Bother? has demonstrated the willingness of people within BME communities to engage, where they feel the process is serious about leading to change. There is clearly a wealth of knowledge and experience that both service users and service providers can bring to a shared dialogue aimed at improving services.

The process itself, of supported group sessions within communities, followed by a facilitated joint session with relevant health service staff, is also one which could be used to engage communities on specific issues, as it met the needs of community participants in addressing the barriers identified and allowing them to contribute. Indeed the project evaluations indicated a real desire to see events and processes such as this continue.

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All projects such as this are of course a small step in an ongoing process of building real, effective and change-orientated engagement between the health service and Black and Minority Ethnic communities. It is our hope that the findings and experience of this project are of use to all participants in taking this important work forwards.

Appendix 1: Plans for implementing recommendations

In the joint workshop, community participants and health service staff drew up plans for implementing three of the community recommendations. The following represent one short-term goal, one medium-term and one long-term. This selection does not indicate that the other recommendations were seen to be less important.

Community Participants:

Demonstrate commitment to change by honestly acknowledging that there are problems

What	Who	How	When
District wide commitment needed	All PCTs, BDCT – whole health and social economy. Assisting role for voluntary sector and communities Human resources staff	Mixture of policy commitment and organisational change. Training needed (events, seminars). Community should be involved in training. Link to performance appraisal. Link to Citizenship Agenda.	Short term Policy / strategy commitment Longer term: develop plan of action and implement

Offer a range of different kinds of opportunities (formal and informal) for individuals to share their views

What	Who	How	When
Community groups and self-help groups Formal and informal mechanisms Diversity of roles	Trusted organisations in partnership Statutory services, across the whole of Bradford's health and social care economy	Resources needed to pay mentors, fund work New roles with responsibility for this provision	Medium term – plan of action to capture diversity of opportunities needed, identifying (and securing) funding

Ensure that participation structures are seen to provide possibilities for change

What	Who	How	When
Evaluate new ways of working	External organisations	Internal audit, measures PDSA cycles	Annual updates
Participatory action research	Patience and Paul ¹³	External evaluation Continuing debate and dialogue with communities Feedback from members of the community	Years 0-2 internal audits, reflections of external organisations and consultants Years 2-3 participatory action research

Service Providers:

Demonstrate commitment to change by honestly acknowledging that there are problems

What	Who	How	When
At start of any local dialogue. Implies willingness to listen to anger about problems (which needs careful management in order to protect staff)	Psychiatrists Frontline staff Senior managers Executive Board	Every time you consult, importance of clarity and honesty. To consider in phrasing of adverts inviting people to participate. At consultation / participation events.	Not short term!!! (issues of who decides, how decision is disseminated, fears about damaging publicity locally if publicly admit to failing communities etc etc)

¹³ Patience Seebohm of the Sainsbury Centre for Mental Health, and Paul Henderson, consultant staff both working with Sharing Voices (Bradford) to carry out a participatory evaluation.

Offer a range of different kinds of opportunities (formal and informal) for individuals to share their views

What	Who	How	When
	<p>Use existing expertise – e.g. SV(B), BAMHAG</p> <p>PPI leads within all NHS organisations</p>	<p>Create ‘coherence’ in consultation, agencies need to work together – there should be one forum attended by senior staff from all agencies</p> <p>More C+VS links, representation, partnership at all levels, to ensure voices are heard at all levels</p>	<p>Needs to be implemented soon – it’s hard to think long-term organisationally because structures and systems are always changing!</p>

Ensure that participation structures are seen to provide possibilities for change

(Not discussed)

Appendix 2: Social and Political Contexts

The need for greater patient influence in mental health service decision-making exists in a social and political context. There isn't space in this report for an in-depth look at these factors and how they influence the ability of communities and individuals to engage in participatory processes. However, two local experts have contributed the following summaries. Dr Philip Thomas, of the Centre for Citizenship and Community Mental Health at Bradford University, looks below at the existing relationship between BME communities and mental health services and at changing psychiatric models, in particular postpsychiatry. He also describes the context of government policy relating to participation in the health service. Paul Henderson (an independent community development consultant) looks at community development models of engagement with regard to BME communities.

Mental Health Services and BME Communities

Dr Philip Thomas

A comprehensive review of this area is beyond the scope of this document, but the situation may be summarised thus. Over the last forty years there have been many hundreds of studies in this country in two broad areas. First, people from BME communities use mental health services in ways that differ markedly from that of the white community. For example, some groups, especially young African-Caribbean men are much more likely to experience compulsory admission, and to have contact through forensic services. Others, especially people from South Asian communities, have been under-represented in mental health services. All groups are less likely to be referred for psychological therapies, and there is an over-reliance on drugs and physical forms of treatment. Second, people from BME communities are more likely to have adverse experiences in using mental health services compared with white people. In its most extreme form, adverse experiences include death whilst in psychiatric care. According to MIND¹⁴ there have been 27 deaths of patients from Black and Minority Ethnic (BME) communities in psychiatric care from 1980 until 2003. This list is almost certainly incomplete because no formal figures are kept.

This is an extremely serious situation, one that resonates with the failure of the Metropolitan Police to challenge and overcome institutional racism in pursuing the investigation into the racist murder of Stephen Lawrence. The murder of Stephen Lawrence and the death of David 'Rocky' Bennett have had profound implications for government policy and thinking about the interface between BME communities and mental health services. David Bennett was a thirty eight year old Rastafarian who died in a medium secure unit on the evening of Friday 30th October 1998, while being restrained by four members of staff.¹⁵ The overwhelming need for change in mental health services is reflected in the following quote which makes clear that services have clearly failed people from minority communities and will continue to do so, unless this failure is actively and comprehensively addressed:

¹⁴ MIND (2003) Evidence to The Independent Panel of Inquiry into the events leading to the death of David Bennett <http://www.mind.org.uk/NR/rdonlyres/7ADC1B4D-1142-4BB5-81F2-6B82008F2341/1151/03bennettevidence.doc> accessed 25th January 2005.

¹⁵ NSC NHS Strategic Health Authority (2003) *Independent Inquiry into the death of David Bennett: An Independent Inquiry set up under HSG (94)27*. Accessed on 22nd January 2005 on http://www.nscha.nhs.uk/scripts/default.asp?site_id=117&id=11516

'We cannot simply rely on applying white models of treatment to improve uptake of existing mental health services. If the Black experience teaches us anything, it may be not good to get more Asians using the existing types of mental health services. What may be more useful is a collective re-think about mental health using culturally relevant ideas.'¹⁶

Psychiatry and Postpsychiatry

Dr Philip Thomas

Postpsychiatry is not another model to compete with the 'medical' and 'social' models of psychiatry. Instead, it points to the possibility (and the growing reality) of a new direction for mental health work, which moves beyond the theories of the 20th century. This move originates in a conceptual critique of psychiatry,¹⁷ and in the growing disaffection of service users and members of Britain's BME communities with mental health practice. Postpsychiatry makes the central claim that many of the problems of psychiatry arise from its identity as an enterprise of modernity. The Enlightenment focus on the individual self charted the course followed by psychiatry for 200 years, with the assumption that all its efforts were transparently for the good. Postpsychiatry holds that psychiatry has been blind to the limitations of its theoretical frameworks, and has overlooked the pain and suffering it can cause. This has practical and theoretical dimensions. On a practical level, postpsychiatry attaches particular importance to work with service users and carers to find new ways of doing mental health work. This happens at macro- and micro-levels. At the macro-level this involves setting up statutory services that genuinely involve collaboration between service user and carer groups, communities (especially Black and minority ethnic communities) and the professionals who serve them.

Government Policy

Dr Philip Thomas

On its election to power in May 1997, the Labour government set about a series of major reforms of health care in England, in which it was determined to forge a new relationship between patients, the professions and the public. These reforms were driven by three principles; reciprocity - that if the quality of services was to improve then staff had to be adequately resourced; accountability - that the public, as tax payers, were key stakeholders in the NHS and, as patients, had the right to a prominent voice in decisions about health care, both locally and nationally; responsibility - the public were encouraged to accept more responsibility for their own health. Related to these principles was a commitment to tackling health inequalities by improving the quality of health care, steps to tackle poverty, especially child poverty. All these changes were set out in detail in the *NHS Plan*.¹⁸ There are two aspects of

¹⁶ Subject interviewed in Walls, P. & Sashidharan, S. (2003) *Real Voices: Survey findings from a series of community consultation events involving Black and Minority Ethnic groups in England*, p.28. Report prepared for the Department of Health, September 2003.

¹⁷ Bracken, P. & Thomas, P. (2001) Postpsychiatry: a new direction for mental health. *British Medical Journal*, 322, 724–727, Thomas, P. & Bracken, P. (2004) Critical Psychiatry in Practice. *Advances in Psychiatric Treatment* 10, 361–370, and Bracken, P. & Thomas, P. (2005) *Postpsychiatry: Mental Health in a Postmodern World*. Oxford: Oxford University Press (forthcoming).

¹⁸ HMSO (2000) *The NHS Plan: A Plan for Investment, A Plan for Reform*. Cm 4818-I, London, HMSO

the NHS Plan that we want to draw attention to. These are its democratic ideals, which stress the importance of accountability and the involvement of the public as citizens, and secondly, the importance it attaches to the social contexts of health care. Although, as we shall see, health care technologies dominate the NHS Plan's attempts to improve the nation's health, it also places patients' interests at the heart of health care. It came into being after extensive consultation to elucidate public concerns about the NHS, and to find out what changes people thought were necessary. Public opinion was that the needs of the system rather than those of the patient dictated much of the work of the NHS:

'While people continue to show real faith in the integrity and professionalism of NHS staff, they see problems in some staff attitudes. Patients feel talked at too much and listened to not enough.'¹⁹

There was a need to see different ways of working in the NHS with a much greater focus on patients' interests:

'For the first time patients will have a real say in the NHS. They will have new powers and more influence over the way the NHS works...'²⁰

This is now being implemented through the Commission for Patient and Public Involvement (PPI) in Health²¹, and the national network of local PPI forums.

The second feature of the NHS Plan is the importance it attaches to social contexts and health. We can see this in the way it draws attention to health inequalities and the impact of poverty on health. In the Plan, the government's attempts to tackle health inequalities play a key part in plans to reform the NHS. It talks about health inequalities in terms of 'injustice' that must be tackled by dealing with their fundamental causes. This means:

'...tackling disadvantage in all its forms – poverty, lack of educational attainment, unemployment, discrimination and social exclusion. *It means recognising the specific health needs of different groups, including people with disabilities and minority ethnic groups.*'²²

However, in view of the alienation experienced by members of BME communities, there are real challenges here for the government's plans for their greater democratic accountability and involvement in mental health services. This challenge is magnified by the Race Relations Amendment Act (2000), which placed a specific responsibility on all public authorities to engage positively and proactively with BME communities, and to tackle social exclusion and discrimination. Consequently, the DH published a flurry of consultation and policy documents. NIMHE's public consultation exercise, *Inside Outside*,²³ was written following twelve consultation events with Black and African-Caribbean, South Asian, Chinese and Irish communities in early 2003. The

¹⁹ HMSO, 2000:135.

²⁰ HMSO, 2000:12.

²¹ See <http://www.cppih.org/>

²² HMSO, 2000:106, emphasis added.

²³ NIMHE - National Institute of Mental Health (England) (2003) *Inside outside* 1/3/03 http://www.nimhe.org.uk/whatshapp/item_display_publications.asp?id=330 accessed 25th January 2005.

Department of Health published a consultation paper, *Delivering Race Equality*,²⁴ which subsequently evolved into an action plan.²⁵ *Inside Outside* spells out the policy context, the Race Relations (Amendment) Act (RRA), which places a duty on all public authorities to eliminate unlawful discrimination, promote equal opportunity and good relations between people from different racial groups. It describes the problems of mental health care experienced by black and minority ethnic groups as follows:

'...that there is an over-emphasis on institutional and coercive models of care;
...that professional and organisational requirements are given priority over individual needs and rights;
...that institutional racism exists with mental health care.'²⁶

It argues that:

'Those who use mental health services are identified, first and foremost, as citizens with mental health needs, which are understood as located in a social and cultural context.'²⁷

The report sets out three strategic objectives; to end ethnic inequalities in mental health care, both in terms of the experience of services and outcome, to develop a mental health workforce capable of delivering effective mental health services to a multicultural society, and to build capacity within the black and minority communities and voluntary sector to respond to the communities' mental health needs. It proposes the use of community development workers as a means of building capacity. The emphasis in *Delivering Race Equality* is slightly different. It sought opinions about a draft framework informed largely by the RRA. The areas of concern flagged up by the document were broadly similar to those raised by *Inside Outside*, but focussed more specifically on suicide, pathways to care and inpatient facilities. It proposed that three fundamental building blocks were essential to improve service delivery and outcome for people from BME communities; better quality information, more appropriate and responsive services, increased community engagement. The final action plan of *Delivering Race Equality* published in 2005 after the publication of the independent inquiry into the death of David Bennett also acknowledged the importance of this report. It promised a five year action plan with the employment of 500 community development workers to engage local communities and build capacity in them.

Most recently, *National Standards. Local Action*,²⁸ in setting out the statutory obligations of PCTs in relation to Patient / User Experience, calls for:

²⁴ DH (2003) *Delivering Race Equality: A Framework for Action 1/10/2003*
http://www.dh.gov.uk/Consultations/ClosedConsultations/ClosedConsultationsArticle/fs/en?CONTENT_ID=4067441&chk=vZZvm%2B accessed 25th January 2005.

²⁵ DH (2005) *Delivering race equality in mental health care: An action plan for reform inside and outside services and the Government's response to the Independent inquiry into the death of David Bennett*
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4100773&chk=grJd1N accessed 25th January 2005.

²⁶ NIMHE, 2003:7.

²⁷ NIMHE, 2003:7.

²⁸ DH (2005), *National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/06 – 2007/08*, p46.

‘Secure sustained national improvements in NHS patient experience by 2008, ensuring that individuals are fully involved in decisions about their health care, including choice of provider, as measured by independently validated surveys. The experiences of black and minority ethnic groups will be specifically monitored as part of these surveys ... PCTs should work with local provider organisations to improve (a) the way people from black and minority ethnic communities are consulted about local health and health care issues and (b) the way their experience is monitored.’

Community Development and BME communities – the national picture

Paul Henderson

Much of the focus of community development over the years has been on inner city areas that experience urban disadvantage, areas in which most members of Black and minority ethnic groups live. Yet it would be misleading to assume that there are therefore strong links between white and Black community development workers.

The community work profession remains overwhelmingly white. Furthermore the UK-wide survey of community development workers carried out in 2002 – 2003 found that Black workers are more often employed within the voluntary sector and less frequently within the statutory sector. The authors state that this is worrying because ‘it may be an indication of the analysis that there is a separation between white and Black community development: they run on different or parallel tracks and communication between them is sporadic’.²⁹ It is argued by some that there is a similar separation between Asian and white community development.³⁰

The experience of community development in Bradford may not match this national picture – there may well be examples of practice that have involved close joint work between white and Black community development workers. Nevertheless it is helpful to bear in mind the wider context when considering the scope and options for developing community participation in health structures and decision-making.

²⁹ Glen, A., Henderson, P., Humm, J., Meszaros, H. with Gaffney, M. (2004) Survey of Community Development Workers in the UK, Community Development Exchange/Community Development Foundation, p57.

³⁰ Manawar Jan-Khan (2003) ‘The Right to Riot?’ *Community Development Journal*, Vol. 38 no. 1 (January) pp.32-42.

Appendix 3: Sharing Voices (Bradford)

The Sharing Voices (Bradford) (SVB) became operational in August 2002, it was known as the Sharing voices initiative at the time. Initially the project was located within a local voluntary sector organisation However since July 2004 it has been operating as an independent organisation with its own premises.

In conjunction with the Centre for Citizenship and Community Mental Health at the University of Bradford, Bradford City tPCT agreed to fund a community development-mental health project targeted at the minority ethnic communities in an effort to develop new thinking and ways of engaging with these communities. Bradford District Care Trust, the main provider of mental health services in the city, also supports the project

SVB uses community development (CD) approaches that are, premised on the belief that poverty, racism, loneliness, relationship difficulties, domestic violence, sexual abuse, spiritual dilemmas are often at the heart of mental health crises. For very many people these issues constitute the core of their problems. Traditional services have some answers but these are often focused on individual interventions in the form of drug treatments or therapy. The problems listed above are essentially social, cultural and economic in nature and cry out for solutions that use different ways of framing, and responding to, difficulties.

CD focuses on improving well-being by addressing economic, social and environmental factors, with a commitment to equality and empowerment. It provides an opportunity for people to acquire skills and confidence in devising their own responses to distress. It fosters a sense of ownership of their services and reduces dependency on others. Cohesion and social inclusion are recognized aims of CD.

AIMS OF SV(B)

- 1) To liaise with statutory service providers and to work together to improve the range and quality of services.
- 2) To stimulate voluntary sector activity in this area, developing capacity within communities and supporting the development of self-help initiatives and community networks. (This is a major part of the teams work and requires active engagement with diverse communities and across communities)
- 3) To stimulate and contribute to local/national and international debates about the nature of mental health problems, diverse perspectives and ethnicity

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Appendix 4: International Centre for Participation Studies

The International Centre for Participation Studies (ICPS) was established in the Department of Peace Studies in 2003. Participation is clearly a key component in building a peaceful society – if we are to achieve the kind of society we want to live in, it must be built from the grassroots up. For this to happen nonviolently, clearly people need real and effective ways to be heard, and to be involved in decision-making. However, participation must be critically explored. Not everything described as participation or community involvement actually leads to real change. The ICPS is interested in exploring what kinds of participation make a difference and contribute to a more peaceful society (that is, one without violence, exploitation and oppression, based on justice, security, equality and respect, and which enables people to fulfil their potential while enhancing that of others).

The aim of the ICPS is to become a flagship academic and practical research unit in the field of participatory politics, located in the Yorkshire and Humberside Region working at the local, regional and international levels. Professor Jenny Pearce is the Director of the ICPS. She is supported by Research Fellow Dr Graeme Chesters, and Programme Officers Heather Blakey and Dr Lucy Brill.

The Centre places a particular emphasis on the connection between academic knowledge and experiential knowledge.

Key priorities for the Centre are:

1. Promoting practitioner access to academic knowledge and skills
2. Assisting practitioners in systematising their experience and knowledge
3. Encouraging the academic valuing of experiential knowledge

The Centre's activities include research, teaching and providing support to practitioners engaged in work around participation.

The ICPS offers a Foundation Degree in Active Citizenship and Participation. This is a two-year workplace based degree. For more information on this, to join our mailing list for information on ICPS research and events, or to find out about any other aspect of our work, please get in touch:

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