Outcomes and Commissioning in Mental Health Services for Black and Minority Ethnic Communities

PROJECT REPORT
August 2007 – January 2009

NHS Bradford & Airedale with the University of Central Lancashire
We keep getting told that what we are doing is really valuable,

But we will only say it is valuable when the actual money

is being put where it is supposed to be put.

That is when we will say: “What we did was valuable”

(Community researcher)
Outcomes and Commissioning in Mental Health Services for Black and Minority Ethnic Communities

PROJECT REPORT
August 2007 – January 2009

Authors: Project Team

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**Further Information**

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Glossary

BME Black and minority ethnic: This includes white groups such as Eastern Europeans and Gypsies and Travellers.

CDW Community development worker.

DRE Delivering Race Equality. This is a five year action plan, introduced by the Department of Health in 2005, to reduce race inequalities in mental health.

FIS Focused Implementation Site: There were 17 FIS areas, including Bradford, which had 3 year projects to fast-track the DRE action plan.

PCT Primary Care Trust.

tPCT In this report this always refers to NHS Bradford and Airedale, formerly Bradford and Airedale Teaching Primary Care Trust.

UCLan University of Central Lancashire.
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Commissioning and participation processes in mental health often fail to cater adequately for service users and carers from Black and minority ethnic communities. This report describes a partnership project between Bradford and Airedale Teaching Primary Care Trust and the University of Central Lancashire which aimed to consolidate, develop and sustain local improvements made through the Department of Health programme, Delivering Race Equality.

The report provides an overview of the 18 month project, describing how service users, carers and others from diverse communities came together with commissioners to carry out the work. It describes in detail the proposals for a commissioning framework and strategy of involvement for people from Black and minority ethnic communities.

The report will be of interest to those who seek to reduce race inequality in mental health services and increase the diversity of service users, carers and others involved in the commissioning process.

In Part One, we set the context in which the project took place, including the background of race inequality (chapter two), policy drivers (chapter three) and the local population in the Bradford and Airedale area (chapter four).

In Part Two, we give an overview of the project, including our aims, the community participants and research activities (chapters five and six).

In Part Three, we outline the proposal for a commissioning framework. After explaining our purpose (chapter seven) we outline the matrix of domains at the heart of the framework (chapter eight). In chapters nine and ten we introduce the outcomes, indicators and process of implementation. Finally, in chapter 11 the tables give information from the research about how the matrix of domains relate to different community groups.

In Part Four, we set out the involvement strategy for BME communities, the rationale for setting up involvement processes targeted at the BME population (chapters 12, 13 and 14) and the detail of the BME Wheel (chapter 15). In chapter 16 we propose how the tPCT might start to develop the Wheel in the immediate future.
Part One: **Background**

1. **Introduction**

The Outcomes and Commissioning Project was a partnership initiative funded by Bradford and Airedale Teaching Primary Care Trust (tPCT) and delivered together with the University of Central Lancashire (UCLan). It was managed as part of the Focused Implementation Site (FIS) project in Bradford, to consolidate, develop and sustain improvements made in the local implementation of the Department of Health programme, *Delivering Race Equality* (DRE).

The purpose of the project was to inform new ways of commissioning and provide opportunities to systematically link the views of people from Black and minority ethnic (BME) communities into the commissioning process. There were two broad aims:

1. To involve members of BME communities, particularly service users and carers, in developing a commissioning framework which would shape the outcomes delivered by local mental health services.

2. To develop and pilot a model for participation which enables BME communities and mental health service commissioners to work together to commission relevant and culturally appropriate mental health services.

Some changes are already in place as a result of the project but further work is being carried out to develop and pilot the proposals for more extensive implementation. This work will continue over the coming year.

The following chapters in Part One of the report describe the background to the project, beginning with the negative experiences of BME communities in mental health services, followed by the policy response and the local context of a diverse population.

2. **Race inequality in mental health**

**Historical perspective**

For many decades studies have reported how people from BME communities experience a lack of respect and understanding in mental health services. The treatment they receive is felt to be neither relevant nor helpful (e.g. Walls and Sashidharan, 2003). The medical model of mental health can appear harsh and oppressive to people from non-Western communities who have other ways of understanding and addressing distress (Bracken and Thomas, 2005). At an individual level, services may be affected by assumptions based on stereotypical views or a lack of confidence in dealing with difference (Keating and Robertson, 2004). ‘Circles of fear’ often characterise the relationship between people from Black communities and their practitioners (SCMH, 2002). The death of David (Rocky) Bennett, a young African Caribbean musician in a mental health unit in 2001 was not an isolated case but a campaign for change led by his sister Joanna created a heightened political awareness of inequality and discrimination in mental health services.

**Delivering Race Equality (DRE) 2005 - 2010**

In 2005, following the Inquiry into David Bennett’s death, the Department of Health (DH) introduced DRE, a five year action plan to reduce fear and improve the response of mental health services to BME groups (DH, 2005). Measures to improve information within DRE include the annual Count Me In census of mental health in-patients. Apart from a notable increase in the number of people described as ‘Other White’ (mainly from Eastern Europe) there has been a consistent pattern among other groups since 2005: White British, Indian and Chinese groups have lower than national average occupancy rates on the wards, while Pakistani and Bangladeshi groups have roughly average levels. Black and White/Black Mixed groups experience higher than average rates of detention and seclusion (Healthcare Commission, 2008a). Length of stay is longest among the Black Caribbean and White/Black Caribbean groups. Locally, there is some variation and we find in the Bradford and Airedale area the numbers of Pakistani men in forensic services give serious cause for concern (see Local Context, Chapter 4).

In Bradford and Airedale, a partnership led by the tPCT set up one of 17 FIS projects across the country to ‘fast-track’ the DRE action plan. In addition to award winning work on improving information, the FIS project created several initiatives to increase the capacity of services to respond to local diversity. For instance, Bradford District Care Trust (BDCT), a FIS partner, commissioned UCLan to deliver staff training on spirituality.

Community engagement is an important strand within DRE, supported by the funding of 500 community development worker (CDW) posts across the country. Eight CDWs in Bradford and Airedale work with different communities, young people and elders, based at Sharing Voices Bradford and Roshni Ghar in Keighley. They aim to reduce the stigma of mental ill-health and build capacity to address mental health issues within communities and public services.
Participation in service design and development

Many feel that it is vital to increase the participation of service users from BME communities in service development to create greater trust, understanding and a more appropriate response. Research in Bradford (Blakey, 2005; Blakey et al, 2006) supported by Sharing Voices examined the barriers to participation in decision-making processes from the perspective of BME mental health service users and carers. The main barrier was a lack of trust, and the belief that statutory services would not listen, or that change would not follow. This was because local people felt that non-medical knowledge was not valued. It was also related to negative personal experiences that many had as patients. In addition, people were conscious of the power structures within the system, and a sense of their own relative powerlessness prevented them from getting involved. Finally, lack of preparation, support and information made it difficult for them to engage with the system in an informed way. The DRE leadership urges commissioners and providers to address these barriers to participation.

A future in the mainstream

The DRE action plan comes to an end in 2010 but the work will not be over: the pressure to push for a better deal for BME groups continues within the mainstream drive for equality and fairness across all groups. The policies now in place, as the next chapter shows, call for commissioners and services to meet individual needs for all their service users, catering for the diversity within their locality. A ‘one size fits all’ approach is no longer acceptable. Progress will be monitored through feedback from service users and the wider community including the ‘seldom heard’ and through the equality impact assessments required by law. The Outcomes and Commissioning Project helps to equip commissioning and participation processes for this future.

3. Policy context

Systematic and rigorous involvement of service users, carers and communities in shaping all aspects of commissioning is a statutory requirement and key developmental challenge for the NHS (DH, 2008a). How it is developed by each PCT should reflect local needs and promote equality across diverse community groups. In particular, the DH recommends that PCTs adopt different approaches with different communities so that they can identify and meet the needs of people who experience the greatest inequalities (DH, 2008a).

This chapter sets out the many policies that steer the tPCT in this field, and shows where our commissioning framework and strategy support compliance.

(i) The NHS Constitution 2009

Legal obligations

Existing NHS obligations, their source and the process for redress if they are not fulfilled are set out in the NHS Constitution (DH, 2009a) and Handbook (DH, 2009b).

All NHS bodies and private and third sector providers supplying NHS services will be required by law to take account of this Constitution in their decisions and actions. (DH, 2009a)

Involvement in service planning

The following paragraphs from the Constitution, with sources from the Handbook, re-affirm recent policies regarding involvement described in more detail below.

You have the right to expect your local NHS to assess the health requirements of the local community and to commission and put in place the services to meet those needs as considered necessary. [Source: NHS Act 2006]

You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services. [Source: Duty to Involve, NHS Act 2006]

On equal terms

The NHS Constitution reminds us that everyone shares the right to be involved and to be treated as equal in this country. As a public authority:

[The NHS] has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.

You have the right not to be unlawfully discriminated against in the provision of NHS services, including on
grounds of gender, race, religion or belief, sexual orientation, disability (including learning disability or mental health).
[Sources include: Race Relations Act 1976 and Equality Act 2006]

In partnership

The commissioning framework and strategy for involvement emphasise the necessity for the NHS to work in partnership with third sector agencies if BME communities are to be involved in service planning and have their needs met. The NHS Constitution reminds us that partnerships are fundamental to the delivery of good healthcare for everyone.

The NHS works across organisational boundaries and in partnership with other organisations in the interests of patients, local communities and the wider population.

The NHS also commits:
• To make the transition as smooth as possible when you are referred between services and to include you in relevant discussions (pledge).
(DH, 2009a)

Informed choice and involvement in personal healthcare

The NHS Constitution reminds us that service users have a right to informed choice and involvement in their own healthcare. Implementation of the commissioning framework, informed by the strategy for involvement, will make this much more possible for people from BME communities.

You have the right to make choices about your NHS care and to information to support these choices.

You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this.
(DH, 2009a)


There has been a gradual shift in policy, bringing involvement to the forefront of the agenda and establishing it as one of the key developmental challenges for NHS organisations (DH, 2008b). Statutory guidance states that public involvement is no longer to be a ‘bolt on’ left to an Improving Patient Experience team, but is to be embedded in all aspects of PCT work (DH, 2008a). The way in which involvement is developed should meet local needs.

PCTs will want to ensure that they and NHS providers adopt a systematic and rigorous approach to seeking, collecting and acting on the views of individuals and partners in the local community, as required by Section 242 – not just during periods of change but on an ongoing basis.
(DH, 2007)

All PCTs should work with their communities to choose an approach that suits their local circumstances.
(DH, 2008a)

The operating framework for 2009/2010 (DH, 2008c) re-affirms the importance of public involvement and the legal status of statutory guidance, Real Involvement (DH, 2008a).

(iii) World Class Commissioning

Every year, PCTs will be assessed on their progress towards achieving the eleven World Class Commissioning Competencies. Their performance will be measured against a number of indicators and over time they are expected to move from a basic level of achievement (level 2) to excellence (level 4).

Although the strategy of involvement would support achievement across several competencies (e.g. 1, 2, 5 and 6), it is particularly relevant to Competency 3:

Proactively build continuous and meaningful engagement with the public and patients to shape services and improve health:

The PCT actively seeks the views of patients, carers and the wider community, forging a long term, inclusive and enduring relationship through a sustained effort and commitment. It makes decisions with a strong mandate from the local population.
(Competency 3)

Assessment of competency 3 and statutory guidance makes it clear that all groups within the population need to be engaged, and that this will require targeted arrangements.

PCTs need to give more thought as to how they will identify and meet the needs of people who experience the greatest inequalities. Addressing inequalities in health outcomes will require
different approaches and styles of engagement with different communities.

(DH, 2008d)

Box 1 shows that our strategy for involvement would help the tPCT to achieve level 4 (excellence) for Competency 3, because it engages ‘hard to reach’ groups. However, it would have a much wider contribution to make, as BME communities in the tPCT area form over a quarter of the local ‘public and patients’ and this proportion is increasing. The strategy, if implemented, will enable the tPCT to include BME communities to an appropriately proportionate level in their work. The strategy therefore makes a substantial contribution to achievement of world class commissioning at all levels.

**Box 1  World Class Commissioning Indicators and tips for Competency 3  (DH, 2008d)**

**Level 4 Indicator for Competency 3**

The PCT has successfully deployed innovative approaches to engagement which have led to high levels of engagement with hard-to-reach groups.

**Level 3 Indicator for Competency 3**

The PCT formally involves patients and public in review of services.

**Level 2 Indicators for Competency 3**

The PCT has effective strategies for communicating with the local population.

The PCT has a strategy in place that actively and continuously engages patients and public in PCT business.

The PCT can demonstrate how local engagement including regular 2 way dialogue with LINks or equivalent patient forums has influenced some aspects of commissioning.

**Level 2 Practical tips for Competency 3**

Have plans to communicate with ‘seldom-heard’ groups and those who are less likely to be able to find contributing easy. Community development will help here.

Use community development to find, support and engage ‘patient’ informants/partners.

When implemented with the commissioning framework, the strategy will help to achieve Competency 6, which concerns prioritising investment according to local needs, service requirements and the values of the NHS. It suggests the tPCT should take a short, medium and long term view of the population and address health inequalities through a thorough understanding of the different sections of their population (DH, 2008).


Section 242 of the NHS Act 2006 set out the ‘Duty to Involve’ for NHS organisations, and this duty was strengthened in 2007. Section 242 (1G) states that NHS organisations should have regard to statutory guidance and have good reasons for any decision to depart from it. Our strategy supports both the legislation and the guidance.

If the tPCT works towards world class commissioning, satisfies the indicators and tips in statutory guidance (Box 1), it will meet its requirements under the duty to involve.

**(v) NHS Next Stage Review – Leading Local Change (DH, 2008b)**

The 4th of the 5 pledges in the Darzi review, Leading Local Change states that:

You will be involved. The local NHS will involve patients, carers, the public and other key partners. Those affected by proposed changes will have a chance to have their say and offer their contribution. NHS organisations will operate openly and collaboratively. (DH, 2008b)

The review argues that proposals for change are stronger when created and shaped by a coalition of patients, the public and staff. It states that ‘different places have different and changing needs’ and that the NHS should develop locally to meet local needs.


The Race Relations Amendment Act requires the tPCT to have due regard to the need to:

- eliminate unlawful racial discrimination
- promote equality of opportunity, and
promote good relations between persons of different racial groups.

When assessing policies for race equality, the tPCT is required to consult with anyone affected by the policy, enabling them to express their views, concerns and suggestions. Our strategy aims to promote good relationships between community groups, and would facilitate community involvement in equality impact assessments and other activities.


DRE aims to improve the access, experience and outcome of people from BME communities in mental health services and the ‘Dashboard’ of indicators, introduced as part of the DRE programme, requires commissioners to monitor progress towards improving these. In 2008, the DRE leadership identified service user and community involvement as a priority for action to support achievement of improved race equality in mental health services. The strategy and commissioning framework are specifically designed to help the tPCT achieve the objectives of DRE by embedding the BME service user voice in the commissioning process.

(viii) NICE: guidelines for community engagement (2008)

The guidelines urge public authorities to take a long term approach to community engagement, identify how this should be funded and lines of accountability. It recommends that community engagement processes should include training for participatory research and evaluation skills.

Recognise that a short-term focus on activities and area-based initiatives can undermine efforts to secure long term and effective community participation.

Identify and provide the structures and resources needed to help community organisations and their representatives participate fully.

In particular, work with groups that may be under-represented and/or at increased risk of poor health, such as black and minority ethnic groups.

(National Institute for Health and Clinical Excellence, 2008)

Overview

Implementation of the proposed commissioning framework and strategy will help the tPCT to demonstrate its commitment to the legal obligations set out by the NHS Constitution. Implementation will help the tPCT to satisfy the requirements of the Operating Framework for the NHS 2008/09. It will help the tPCT to deliver World Class Commissioning, in particular the strategy will help to satisfy indicators for Competency 3 at levels 2, 3 and 4 and the framework will help to achieve Competency 6.

Overall, the ‘one size fits all’ approach in the NHS has been replaced by a requirement to adapt to the local population, and the next chapter sets out the local context.

4. Local context

Approximately a quarter of the population in the tPCT area has a BME heritage (25.1% including the 1.9% of mixed heritage, ONS 2008, see Box 2 below). The proportion of people with a BME heritage has increased from 2001 to 2006 and this trend is likely to continue. These figures suggest at least one in four of the people served by the tPCT have a BME background. Some areas within the tPCT have a much higher proportion of people from BME backgrounds and it is anticipated that BME groups will form the majority in these areas at some point in the not very distant future.

Within BDCT the number of service users with a BME heritage on the adult wards is disproportionately high, reflecting the national picture. BDCT has been unable to provide this project with an analysis of their in-patient data, but an analysis of the figures that we have received, covering a 9 month period, shows the proportion of people from a BME background on the adult wards ranged from 28% to 39% (average 33%) and on the forensic wards the proportion ranged from 35% to 48% (average 41%) (March – November 2008, percentage rounded to nearest whole number). The growing number of in-patients describing themselves as ‘White Other’ is of particular concern locally as it is nationally. The number of Pakistani men on Bradford’s forensic wards (approximately 30% in the 9 month period, March – November 2008) must be a grave concern locally, particularly as it does not reflect the national picture.

There is little involvement of BME service users in tPCT or BDCT participation activities or feedback surveys, except ad hoc community engagement events which, on their own, do not meet statutory requirements or provide the quality of information needed to plan appropriate services. Responses in 2008 to the annual Healthcare Commission community mental health survey failed to reflect the BME perspective, with 96% of respondents White British, 1% Asian, 1%
Black, 1% mixed and 1% ‘Chinese or other’ (Healthcare Commission 2008b). This level of BME involvement is half of the average found across the country.

The current lack of BME involvement means that tPCT commissioners do not know if the services they fund meet the needs of between a quarter to a third or more of those people who might use them. Due to the increasing BME population in Bradford, this situation will worsen over the next 5 years if it is not addressed. The next section of the report provides an overview of our project which set out to address this problem.

Box 2  Resident population estimates, 2006
Source: ONS Neighbourhood Statistics
www.neighbourhood.statistics.gov.uk
Last updated January 2009

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<th>Ethnicity</th>
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<tr>
<td>Black</td>
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<td>Caribbean</td>
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</tr>
<tr>
<td>African</td>
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<tr>
<td>Other</td>
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<td>Chinese and other ethnic groups</td>
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</tr>
<tr>
<td>Chinese</td>
<td>0.5%</td>
</tr>
<tr>
<td>Other ethnic groups</td>
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</tr>
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</table>
5. Project aims and participant experience

The overall purpose of the project was to create sustainable change in provision for people from BME communities by embedding their views in the commissioning process. The aims were therefore:

1. To involve members of BME communities, particularly service users and carers, in developing a commissioning framework which would shape the outcomes delivered by local mental health services.

2. To develop and pilot a model for participation which enables BME communities and mental health service commissioners to work together to commission relevant and culturally appropriate mental health services.

A number of activities took place to help us achieve these aims, of which the most important were (a) the recruiting, training and involvement of 24 participants; (b) carrying out the community research and a review of published research; (c) working with the tPCT to draft a commissioning framework and (d) developing a strategy whereby commissioners and people from BME communities can work together in the future.

Participants

Ethical approval was granted by Bradford Research Ethics Committee in August 2007 and shortly after that, the project began to recruit participants. Of the 24 people who joined, 16 were women and eight men, aged from 22 to 57 years old. A third of participants were current or past users of mental health services, nearly a third were carers of people with mental health problems and others included asylum seekers, refugees, women with experience of domestic abuse and people working or wishing to work with people with mental health problems. There was a wide range of educational experience and ethnic background among participants:

- 13 South Asian (Pakistani, Bangladeshi, Kashmiri)
- 4 African Caribbean/Black British
- 2 Irish (one born in Bradford, one born in Ireland)
- 2 Polish (one born in Bradford, one born in Poland)
- 1 African, 1 Iranian and 1 Iraqi.

University training and awards

A Policy and Participation course, delivered over nine local workshops by UCLan, was a cornerstone of the project. It aimed to develop students’ awareness of social policy and organisational structures in the public sector and develop the skills and knowledge necessary for effective engagement with statutory sector agencies. Training in presentation skills delivered by a local drama teacher complemented the course.

Twenty of the 24 participants gained university certificates, including 16 at the highest level, with four gaining distinction and five gaining merit. Four participants received the University Certificate of Achievement in Community Engagement.

The participant experience

All the activities and most meetings during the project involved community participants. About 15 individuals were actively involved throughout and chose to participate in different ways. Some joined the community research team, some attended workshops to develop the strategy of involvement, some contributed to the UCLan training for commissioners, and some attended meetings with commissioners, tPCT staff, the project steering group and visitors from the national Delivering Race Equality programme.

Feedback on the overall project was positive, with participants valuing the opportunities to meet commissioners, carry out research and learn more about mental health. Several said that they gained a good background to statutory services and greater confidence in helping to improve them. They valued the skills and knowledge that they gained.

The most frequently mentioned benefit of the project was the opportunity to meet and work with such a wide variety of people. Participants were surprised to find how much they had in common with people from very different backgrounds.

Six participants progressed in their careers during the project, with five taking up full, part time and sessional employment and one increasing her hours of work. Involvement in the project may have been a contributory factor in this and we firmly believe that most involvement opportunities, if well supported by community workers and NHS staff, will help individuals to achieve what they want in their life.

I got involved in the Policy and Participation course and, to be honest, at first I thought I might not finish it. But I got a lot of encouragement during the course...
...and support ...and I’ve completed it and stayed involved after it finished because I enjoyed it and want to help make services better. I feel my opinions and contribution is valued and I’ve learnt a lot about mental health services.

(Kulvinder: Participant Report)

I was very nervous at first and never thought I would have the courage or ability to do the course. I wanted to do the course for myself but I also want to use this experience to help support people, to share their problems and feel better about themselves and to make sure there are good services in Bradford that can do this. ....It was great to meet so many different people from different cultures. We share so many things and ideas about what makes good services and if we work together, I believe we can make our suggestions heard.

(Kalsoom: Participant Report)

I learnt about different cultural issues, many of which I found to have similar themes to my own cultural identity and background, the main two being spiritual needs and the extended family networks of support. As the project progressed, it was clear to me that whilst there were many differences between the different cultural groups I met, there were also many commonalities and we shared many social issues which affect our mental health….Most of all, I enjoyed the comradeship of all the people involved in the project.

(Tony: Participant Report)

6. Research

Purpose

The primary purpose of the research was to inform the commissioning framework by gathering the views of local people from BME communities. The mental health commissioners wanted to find out from local BME groups:

• What factors contribute to their emotional wellbeing?
• If they feel sad, distressed or if they are experiencing an emotional crisis and cannot cope with their life, what helps them to regain a sense of wellbeing?

A secondary but important purpose of the research was to build capacity within local communities by developing the research skills of local people and by creating new links and increased interest around mental health issues. The work was therefore pragmatic and developmental, but at the same time, it aimed to be rigorous and delivered to a good academic standard.

Community research methods and process

Nine of the 24 project participants chose to become community researchers and they attended weekly meetings over six months. We invited experts from the voluntary and statutory sector to advise us on which groups we should prioritise, why, and where we would find them. Community researchers were trained in running focus groups and identified sites within their communities where these could take place. CDWs and other community workers facilitated access to local people and in some cases, took a lead role in organising the groups. Interviews were used for Gypsies and Travellers and Muslim women with experience of domestic violence because this was their preference.

With participants’ permission, focus groups and interviews were taped, fully transcribed and a content analysis was guided by the research questions. Expert advisors and community researchers discussed the findings, to identify any gaps, interpret the data and agree recommendations. These discussions were immensely helpful and we owe much to the expert advisors and community researchers who took part.

The selection process to decide which groups to include took account of the following factors:

• In part the choice of which groups to include was made for us by local community experts who advised us on which communities, gender and ages should have priority.
• For commissioning purposes, we sought to gain as diverse a spectrum of opinion across BME communities as possible.
• To support the developmental aspect of the project, we wished to develop the capacity of the community researchers to bring groups together around mental health issues in their locality and community.
• Resource constraints limited the size of the study.

Resources did not permit a detailed study of any particular community group, but our findings were felt to be fair by group members and community experts.

The numbers of people involved suggest that we gained a good cross-section of views across the local BME population. In total, there were 16 focus groups and 16 interviews,
involving 135 people comprising 59 men (44%) and 76 women (56%). Ages range from under 22 to over 60. Ethnicity of those who took part is given in Table 1.

Table 1 Ethnicity of people who took part in focus groups and interviews

| 63 South Asian and other Asian | 34 Pakistani, 15 Bangladeshi, 7 Indian and 7 Asian ‘other’ including Iranian and Iraqi |
| 29 Black African, Black Caribbean and other Black | 12 Black African 16 Black Caribbean, 1 Black other |
| 10 Mixed ethnicity | 7 Caribbean/White, 1 African/White, 1 Asian/White, 1 Other mixed |
| 16 ‘White other’ and Irish | 11 Polish, 4 Gypsy or Romany, 1 Irish |
| 12 White British | Including 5 travellers and 7 with Polish heritage |
| 5 Other and missing data | 2 ‘Other’ (Female asylum seeker’s group) 2 missing data (Caribbean young men’s group) 1 missing data (Muslim woman/domestic violence interview) |
| 135 Total | |

From this data, we produced nine reports of varying size on the following groups:

- South Asian men
- African and Caribbean groups
- Polish groups
- African Men
- Asylum seekers and refugees
- South Asian women
- Male African and Asian service users
- Muslim women with experience of domestic violence
- Gypsy and Traveller Women.

We hope these reports will inform and encourage new initiatives and greater partnership working between the TPCT, health providers and the third sector.

**A matrix of shared factors for wellbeing**

To support the commissioning framework we identified 15 domains, aspects of life, identified by most of the groups, which were important factors in wellbeing and sources of support in times of emotional difficulties. These are described in detail in Part Three.

**The literature reviews**

Three literature reviews were carried out by Professor Philip Thomas to broaden the evidence base and investigate the validity of our findings by comparing them with large published studies of mental health and recovery, mainly but not only in BME groups. He found that the research literature confirmed and helped to explain our findings.

**The literature review I: Mental health inequalities**

The purpose of the first review was to outline and summarise the key literature on mental health inequalities experienced by people from BME communities. This is a vast area and so the review focused on issues particularly relevant to implementation of DRE and this project. We summarise the main points emerging from this review as follows:

- There was clear evidence that people from BME communities with mental health problems had different pathways into primary and secondary care.
- There was evidence that some groups (especially Black people) were more likely to be diagnosed with psychoses, especially schizophrenia. Recent thought has shifted away from the view that this represents a fundamental biological (racial) difference between Black and White people.
- There was also clear evidence that people from BME communities, especially African Caribbean people had lower levels of satisfaction with mental health services.
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- There was also clear evidence that people from BME communities, especially African Caribbean people had lower levels of satisfaction with mental health services.
- Recent work suggested that racism (perceived and experienced) was an important factor leading to higher rates of all forms of mental disorder and poor health more generally, especially in Black people.
- Some people from non-Western cultures who live in Britain appeared to have different explanatory frameworks of mental health compared with white British people.
- In broad terms people from non-Western cultures were much more likely to hold spiritual (or moral) and/or social (family) explanatory frameworks.
These findings appeared to be robust for West African and South Asian people, irrespective of whether or not they were in contact with mental health services. The findings also appeared to hold for depression and conditions such as schizophrenia.

The literature review II: Outcome measures in mental health

The second literature review presents evidence that the standardised outcome measures used for commissioning and clinical purposes should be complemented by subjective outcome measures that reflect the concerns of service users. It proposes that the concept of face validity is useful in understanding how subjective measures differ from and complement standardised (or objective) measures. Subjective outcome measures have been shown to have high levels of predictive validity for patient satisfaction. This is useful given the strong evidence that objective measures, such as standardised needs assessments, have little benefit in terms of subjective outcomes.

The literature review III: Explanatory models, coping strategies and recovery

This built on the earlier reviews by exploring the concept of recovery as an important outcome as far as service users are concerned. It found that how recovery was defined by service users depended on the individual, especially his or her explanatory framework. The studies reviewed here have not specifically investigated recovery in people from BME communities. However, Review 1 indicated that the diverse explanatory frameworks of people from BME communities in England almost certainly played a key role in the recovery of these groups.

The frameworks that people found helpful in terms of recovery were spiritual, social, personal narrative and medical. The ability and opportunity to use explanatory frameworks in negotiating meaning and coming to an understanding of one’s experiences was also a key feature of recovery in these studies. It was also clear that people often hold different explanatory models at the same time, even though these may be mutually contradictory. In addition, within each individual, explanatory models change with time. These are not fixed, static features of people’s lives. They change and evolve depending on many factors. This means keeping track of what people find helpful over time is really important. Practitioners cannot afford to stand still; they must keep up with people’s needs as these change over time.
7. Purpose

This framework aims to help commissioners address inequalities in mental health services and guide service development towards individualised, appropriate and responsive care for people from BME backgrounds. It aims to increase satisfaction and thereby increase confidence in services, improving access, experience and outcomes.

Although the focus of our work was to develop an outcome-focused framework for commissioning purposes, as the work progressed we identified a ‘matrix of domains’ which describes both the outcomes that local people say they want and the inputs that they say help them to achieve these outcomes. This matrix can therefore be used to guide mental health practitioners and others in the way that they support individuals who are experiencing mental health problems, giving the framework unexpected ‘added value’.

A project team including mental health commissioners and project participants produced initial ideas then consultations took place with a range of commissioners and providers. Further work is required to develop the proposal for implementation. Future reviews of community perspectives and statutory obligations will ensure it remains relevant.

What does the framework offer?

The framework encourages a recovery focused approach, based on the understanding that recovery from mental ill-health is a journey where the direction and pace are set by the service user. People from BME communities have told us what outcomes and help they want when experiencing distress or severe mental ill-health to make them feel better about themselves, inspire hope and help them to cope with their daily life and mental health issues. This information has been used to produce a guide for commissioners, service managers and practitioners who seek to deliver the kind of support people want.

We have devised indicators which give the service user’s perspective on their progress towards their chosen outcomes. These indicators aim to complement existing standardised measures used for service benchmarking, such as HoNOS.

Finally, the framework includes a process for commissioning in which local people from BME communities play an active role, thereby contributing to their own recovery while helping commissioners promote recovery across the BME service user population. Our strategy for BME involvement (Part 4) sits alongside this commissioning framework to support this process and used together, they can lead to a greater emphasis on and achievement of recovery for service users from BME communities.

How to follow the framework through Chapters 8 to 11

There are five steps set out in the following chapters for commissioners, service managers and practitioners who wish to follow how the framework can be used.

Chapter 8: Matrix of Domains is the central component of the framework. It is based on the community research and sets out the outcomes and the kind of help which people from BME communities said that they want from their support services. We describe the 15 domains of the matrix and explain how they can be used to improve services for people from BME backgrounds.

Chapter 9: Outcomes and indicators translate the domains into identifiable and measurable outcomes. We propose indicators which measure progress, from the service user perspective, in achieving the desired outcomes.

Chapter 10: Process and implementation shows the steps that commissioners and practitioners take when using the framework, and how the strategy for involvement of BME communities enables people from diverse communities to play an active role in this process.

Finally, Chapter 11: Domains in more detail draws on the research evidence to suggest how the framework might be applied for the benefit of people from some local BME communities. Tables provide information across the domains and notes from consultations provide more detail on employment, spirituality and individual budgets.

8. Matrix of Domains

The 15 domains

In order to find out what people would find helpful in their journey of recovery and what outcomes they might pursue we consulted 135 people from BME communities in Bradford. We asked them what contributes to their wellbeing and what helps them to achieve this when feeling low or experiencing severe mental ill-health. We found that across all the communities the views were quite similar and we identified 15 ‘domains’ which cover both the outcomes that they want and the help (input) that contributes to achieving
these outcomes (Table 2). We have brought these together in what we call a matrix of domains.

Table 2 Matrix of 15 domains

<table>
<thead>
<tr>
<th>Primary domains likely to be relevant as outcome and input to most people from BME communities</th>
<th>FAMILY</th>
<th>SPIRITUALITY</th>
<th>WORK/ WORTHWHILE ACTIVITY</th>
<th>COMMUNITY AND SOCIAL RELATIONSHIPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary domains likely to be relevant as inputs or outcomes: people may differ more in their choice</td>
<td>EDUCATION</td>
<td>CREATIVE ACTIVITY</td>
<td>EXERCISE</td>
<td>HOME &amp; PERSONAL SPACE</td>
</tr>
<tr>
<td>‘Pre-requisite’ domains - inputs &amp; outcomes related to these are needed by all those who have difficulties in these areas</td>
<td>FINANCIAL SECURITY</td>
<td>TRANSPORT &amp; ACCESS TO SERVICES</td>
<td>RESPECT &amp; SAFETY</td>
<td></td>
</tr>
<tr>
<td>Help domains inputs and outcomes which help - in preventing problems, dealing with problems and in crisis</td>
<td>IN CONTROL/ INFORMED CHOICE</td>
<td>SAFE SPACES &amp; TRUSTED PERSON TO TALK TO</td>
<td>MUTUAL SUPPORT</td>
<td>APPROPRIATE PHYSICAL &amp; MENTAL HEALTHCARE</td>
</tr>
</tbody>
</table>

Explaining the matrix

The domains are essentially broad areas or aspects of life which are important in relation to the mental health and wellbeing of those we consulted. If all is well within these aspects of life, then they told us their quality of life will be good. Problems in these areas could contribute to distress and poor mental health. The problems may become so severe that people feel that they cannot cope with their life anymore. The outcome that they want from their support services is the resolution of their problems within one or more of the domains. The help that they feel is relevant may also be found within one or more of these domains. So although appropriate mental healthcare may be one type of help they want, it is unlikely to be the only kind of help that they need to recover from their problems. The matrix therefore provides a guide to the type of support services local people from BME groups might want.

Not every domain is of importance to every person. Our research suggests that the top row (family, spirituality, work/worthwhile activity and community/social relationships) are of central importance to most people from BME communities, while people differed more in the importance they attached to the domains in the second row. This may be because their needs, for instance for a home, had been met and were not at the forefront of their minds. For those who do not have a good home, this issue will be of paramount importance. The domains in the third row were often essential pre-requisites to self determination and fulfilment. Difficulties found here need to be dealt with if wellbeing is to be improved. The bottom line (safe spaces, trusted person, mutual support and appropriate healthcare) were the most frequently mentioned sources of help in times of difficulty but they were also important in the prevention of mental ill-health. If people have access to people they trust, support from their peers, places to go where they could talk freely (perhaps in their own language) and good care from their...
GP, then difficulties could be resolved at an early stage and this would contribute to a good quality of life.

The research suggests community groups tend to differ in their priorities and in what they mean by each domain. Although there may be broad similarities within a community group (for instance many Muslim women may want spiritual support), this does not imply that every individual in the group thinks the same way. Cultural profiling of diverse communities can mislead those working with individuals. This matrix is intended to support individually tailored packages of care based on the wishes of each service user.

The matrix is not prescriptive and may not cover all the important issues for every service user. Practitioners may find that a service user wants a different response not listed here, and if this is recorded under the ‘Any other domain’ box it may contribute, in time, to a review of the matrix. We recommend a review takes place every two or three years.

How the matrix helps to improve services for BME communities

The domains within the matrix are probably relevant to people from all communities. Current policy on the refocused CPA already encourages practitioners to ask their service users about a broad range of social issues that may be troubling them. How will this matrix make a difference to people from BME communities?

We believe that the matrix, combined with other elements of the framework, will improve services for people from BME communities (and others) if:

1. The assessments of service users enable them to explore, within their own cultural and social context, which domains are relevant to them, what outcomes they want, and what interventions are needed to achieve their chosen outcomes.
2. The response offered by service providers is perceived by service users to be relevant and useful. The matrix provides a guide as to what might be useful.
3. The indicators of improvement in mental health and achievement of the desired outcome include those based on the service user perspective.
4. Service user views, particularly those given to independent community based researchers, are given priority by commissioners and others in their monitoring and review exercises.

The following points, backed up by published research and policy requirements, may help to explain the importance and significance of these four actions:

- The heritage and background of the service users shape their understanding of the causes of and solutions to mental ill-health. Interventions are known to be more successful if they are perceived to be relevant. Therefore, although the problem areas (family, work, etc) may appear similar for many service users, the solutions may differ according to heritage and background.

- The framework assumes that mental health practitioners act as enablers¹, creating opportunities for service users to access a wide variety of different kinds of help. Partnership working, combined with a vibrant, diverse service economy will be required and it is anticipated that these will develop over time. Bradford has some innovative community based projects, but there is a need for more collaboration within and across the sectors. An effective use of individual budgets will also help to provide the flexibility and individually tailored support that service users want. An increased use of individual budgets will support implementation of the framework.

- Third sector and community agencies offer a different approach which cannot be replicated within statutory services, even if NHS practitioners have a BME background. Statutory services require a professional approach which is grounded in a medical or psycho-social framework. There may be barriers to communication and trust between people from BME communities and statutory service staff, even where there is a shared language.

- Partnerships between statutory services and third sector projects can be helpful in overcoming these barriers, for instance with shared assessments, enabling service users to reflect more comfortably on their health issues. Regular liaison between partners will provide a more coordinated service than making a referral and transferring responsibility for support to the partner agency. It is important that partnership working does not result in fragmented care for the service user.

- This framework encourages psychiatrists and GPs to give service users and patients more choice about the help they receive in support of Our Choices in Mental Health, (CSIP, 2006a). World class commissioning requires commissioners to engage with clinicians on the service they provide for local people (DH, 2008d).

¹ Department of Health (2008) Refocusing the Care Programme Approach
• Regular feedback from BME (and other) service users provides the best guide to whether or not practitioners, managers and commissioners are getting it right and providing the care that they want. Existing feedback mechanisms and satisfaction surveys tend to provide little useful information about the views of BME service users. The policy on world class commissioning requires a two way communication between local communities and their commissioners (DH, 2008d).

For a deeper understanding of these points, see the literature review by Professor Philip Thomas, available on the website: http://www.bradfordairedale-pct.nhs.uk/Equality+and+Diversity/Innovation+and+best+practice/BME+Mental+Health+Commissioning/

The domains and BME communities

As explained above, individuals will differ in the domains relevant to them, in the aspects of the domain which trouble them and in the help that they feel useful. It is not possible to infer that a particular individual will want a certain response because they belong to a particular group, such as being a Muslim. However, there are some issues that were prominent in the research and these may – or may not - arise for any particular individual. Table 3 illustrates some of these issues. More detail about what different groups want can be found in Chapter 11 and in the research papers available on the website (see back page).

Table 3 The issues that may arise for people from BME communities

<table>
<thead>
<tr>
<th>Family</th>
<th>Spirituality</th>
<th>Work/worthwhile activity</th>
<th>Community &amp; social relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family ties and roles can be</td>
<td>Spiritual support may come from</td>
<td>Racism reduced the chances of</td>
<td>People said that spending time with</td>
</tr>
<tr>
<td>much more important in non-</td>
<td>religious leaders or from trusted</td>
<td>getting or keeping a job and this</td>
<td>others, especially those</td>
</tr>
<tr>
<td>Western societies and may</td>
<td>others. It is important to many</td>
<td>had a severe impact on families.</td>
<td>from their peer group helped</td>
</tr>
<tr>
<td>be threatened by life in the</td>
<td>people from BME communities especially</td>
<td>Many people felt that working</td>
<td>them feel good. They also</td>
</tr>
<tr>
<td>UK. For some people, a family</td>
<td>South Asian and older generations. It</td>
<td>for their community (unpaid) was</td>
<td>valued integration and good</td>
</tr>
<tr>
<td>approach to their emotional</td>
<td>is a primary source of help for</td>
<td>extremely worthwhile and</td>
<td>relationships in their</td>
</tr>
<tr>
<td>problems could be very helpful.</td>
<td>many difficulties.</td>
<td>important to them.</td>
<td>neighbourhood.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Creative activity</td>
<td>Exercise</td>
<td>Home and personal space</td>
</tr>
<tr>
<td>ESOL or college were needed</td>
<td>Creative activity was felt to be an</td>
<td>Many were self-motivated but</td>
<td>Overcrowding was said to affect</td>
</tr>
<tr>
<td>for careers and integration,</td>
<td>important way of restoring and</td>
<td>others were more likely to exercise</td>
<td>mental health. Asylum seekers, new</td>
</tr>
<tr>
<td>both important for wellbeing.</td>
<td>promoting good mental health. Music,</td>
<td>when given informal support within</td>
<td>refugees &amp; migrants may have major</td>
</tr>
<tr>
<td>Cost of childcare and classes</td>
<td>crafts and cinema were often</td>
<td>each age/ethnic group. Gyms can be</td>
<td>problems with their housing.</td>
</tr>
<tr>
<td>could be prohibitive.</td>
<td>mentioned.</td>
<td>too costly.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial security</td>
<td>Transport &amp; access to services</td>
<td>Respect &amp; safety</td>
<td>(Any other domain)</td>
</tr>
<tr>
<td>Many said financial worries</td>
<td>Issues raised included difficulties</td>
<td>Racism was reported in all public</td>
<td></td>
</tr>
<tr>
<td>could precipitate emotional</td>
<td>travelling to services &amp; being</td>
<td>settings, seriously affecting</td>
<td></td>
</tr>
<tr>
<td>problems. Discrimination in</td>
<td>understood by service staff. Taxi</td>
<td>mental health. It was especially</td>
<td></td>
</tr>
<tr>
<td>the job market exacerbated</td>
<td>drivers can gossip in the community.</td>
<td>difficult to get help for abuse in</td>
<td></td>
</tr>
<tr>
<td>difficulties.</td>
<td></td>
<td>the home.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In control/having choice</td>
<td>Safe spaces and a trusted person to</td>
<td>Mutual support</td>
<td>Appropriate physical &amp; mental</td>
</tr>
<tr>
<td>People wanted to be able to</td>
<td>talk to</td>
<td>People were keen to give and</td>
<td>healthcare</td>
</tr>
<tr>
<td>choose the support they</td>
<td>People wanted a place to go where they</td>
<td>receive support from their peers, e.g.</td>
<td>Several wanted culturally relevant</td>
</tr>
<tr>
<td>received, and get the</td>
<td>felt safe, at ease &amp; able to talk</td>
<td>share ethnicity, age, gender, mental</td>
<td>talking and bereavement</td>
</tr>
<tr>
<td>information they needed</td>
<td>about personal matters, often in their</td>
<td>health issue or experience. Giving &amp;</td>
<td>therapies, in their own language.</td>
</tr>
<tr>
<td>to make that choice, e.g.</td>
<td>own language. Safe spaces were found</td>
<td>receiving both help to promote</td>
<td>Some felt hospital care for mental</td>
</tr>
<tr>
<td>information on side-effects</td>
<td>at community projects.</td>
<td>wellbeing.</td>
<td>health problems lacked cultural</td>
</tr>
<tr>
<td>and alternatives to</td>
<td></td>
<td></td>
<td>and spiritual understanding.</td>
</tr>
<tr>
<td>medication.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

OUTCOMES AND COMMISSIONING PROJECT 21
9. Outcomes and indicators

Defining the outcomes

We have defined outcomes in the same way across the matrix, regardless of the domain to which they refer. They can be identified at different stages in the individual’s journey. The nature of the outcomes differs according to the level at which they are considered.

Table 4 Defining the outcomes

<table>
<thead>
<tr>
<th>LEVEL</th>
<th>OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMMISSIONING</td>
<td>Assessments which service users feel</td>
</tr>
<tr>
<td></td>
<td>- Enable and encourage them to explore what issues are affecting their mental health.</td>
</tr>
<tr>
<td></td>
<td>- Enable them to identify the goals they wish to pursue to address these issues.</td>
</tr>
<tr>
<td></td>
<td>- Demonstrate an understanding of their cultural, spiritual and social needs.</td>
</tr>
<tr>
<td>SERVICE/ORGANISATION</td>
<td>Service responses which service users feel</td>
</tr>
<tr>
<td></td>
<td>- Enable them to make an informed choice about the service or individual funding they get.</td>
</tr>
<tr>
<td></td>
<td>- Provides the service or individual funding that they have chosen.</td>
</tr>
<tr>
<td></td>
<td>- Is useful, respectful and takes account of their cultural, spiritual and social needs.</td>
</tr>
<tr>
<td>PRACTITIONER</td>
<td>Changes in mental health which service users feel</td>
</tr>
<tr>
<td></td>
<td>- Indicate they have achieved their personal goals or are likely to do so with continuing support.</td>
</tr>
<tr>
<td></td>
<td>- Have been supported by a flexible response to their changing needs.</td>
</tr>
<tr>
<td></td>
<td>- Have enabled them to cope better with their mental health and emotional issues.</td>
</tr>
<tr>
<td></td>
<td>Partnership working which service users feel</td>
</tr>
<tr>
<td></td>
<td>- Provides staff who work together well as a team and demonstrate their commitment to providing appropriate support at all times.</td>
</tr>
</tbody>
</table>

The scorecard of indicators

The service users’ response to the statements in table 5 (right) can be used to find out how well services are performing, from the service user perspective, across all the domains. All statements require a yes or no answer, depending on whether or not the service user feels they are true, and scores can be aggregated. The timeframe for asking the questions might depend on the particular purpose for which this is being carried out. For instance, the scorecard can be used for feedback from the service user to their practitioners, and this might be relevant on a monthly basis, depending upon how often they are meeting.

When the individual scores are aggregated together, the overall scores can be used to monitor the performance of a service. Commissioners and service managers might wish to see monitoring data aggregated quarterly or every six months. Due to the turnover of service users, we suggest that the data from each quarter is independent of the quarter before and the quarter that follows. An increase in total quarterly scores over a one or two year period will indicate services are increasingly meeting the needs of BME service users.

Aggregated scores from individual teams within an organisation could be compared with other teams, to identify good or poor practice and promote peer learning, again on a six monthly basis. Managers might find this a useful way to promote service improvements for people from BME groups.
The scorecard can be adapted to provide a semi-structured interview for use when reviewing a target area (see Chapter 10).

Who is asking the questions on the scorecard?

When the scorecard is being used to provide feedback from service users to practitioners, it is practical that the questions should be asked by those providing the service, who will be mental health practitioners and perhaps staff within partner agencies where these are involved on a regular basis. There is a significant risk that service users will be reluctant to give critical feedback to their service provider. As part of the development of the framework, it is suggested service providers are asked to explore scope for an alternative person to complete the form with the service user.

When the scorecard is being used as a monitoring tool, it would be useful to carry out ‘spot checks’ of the scores by arranging for BME community researchers to ask the questions to a sample of service users, for instance covering the service users of one team or service area every quarter. If there are differences when the results of practitioner-collected and researcher-collected scores are compared, then the possible remedies for this can be explored. The scores given to community researchers are more likely to be true representations of the service user view and should be given greater weight by commissioners.

Table 5 Indicators of the service user perspective

<table>
<thead>
<tr>
<th>LEVEL</th>
<th>COMMISSIONING</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Measuring improving outcomes</strong></td>
<td>1. Quarterly monitoring data collected by service providers</td>
</tr>
<tr>
<td></td>
<td>2. Annual survey of a representative sample of BME service users; questionnaires completed face to face with community researchers on the ward and in non-clinical settings.</td>
</tr>
<tr>
<td><strong>Exploring barriers &amp; good practice</strong></td>
<td>• Semi-structured interviews by community researchers of samples in target areas, agreed with providers.</td>
</tr>
<tr>
<td></td>
<td>• Workshops of all stakeholders to discuss findings and next steps.</td>
</tr>
<tr>
<td><strong>Developing partnership working</strong></td>
<td>• Include question in monitoring and in annual survey of BME service users on team working. Review findings.</td>
</tr>
</tbody>
</table>

| INDICATOR (Yes/No answer required) | |
|----------------------------------| |
| **Assessment/Stage one:** | 1. I have had help and encouragement to think about what is affecting my mental health or emotional wellbeing. |
| | 2. I feel my cultural, spiritual and social needs were understood sympathetically and acted on by those helping me. |
| | 3. I have been helped to choose the goals I would like to pursue to improve my mental health or emotional wellbeing, i.e. these goals have not been set for me by the professional staff. |
| **Service response/Stage two:** | 4. I have been given enough relevant information, in a form and language I understand, to make a choice about the kind of help I could receive to achieve my goals. |
| | 5. I have been given individual help to choose the service or funding that I believe will help me to achieve my goals, and I have started to receive the service or funding. |
| | 6. I feel that the help I have received has been useful, respectful and took account of my cultural, spiritual and social needs. |
| **Change in mental health and wellbeing/Stage three and later:** | 7. The goals I selected have been met fully or I am hopeful and expecting that they will be met fully with the continuing support that I am receiving. |
| | 8. I have been given full support to discuss and change the help that I receive and the goals I am pursuing, when I want to do so. |
| | 9. I can now cope better with my mental health/emotional problems. |
| **Experience of partnership support:** | 10. I feel those supporting me have worked together well as a team, and they have shown by their actions that they want to give me the most appropriate support at all times. |
The scorecard of the community resources

The record in Table 6 provides feedback to commissioners and service managers on the availability of local resources and quality of partnership working required to respond appropriately to people from BME communities. It can be completed by mental health practitioners and staff in other organisations funded by the tPCT on a weekly basis and aggregated by providers quarterly.

Table 6  Scorecard of Community Resources (with examples)

<table>
<thead>
<tr>
<th>Community resource required</th>
<th>Agencies responding well</th>
<th>Area for improvement or investment</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESOL for person using mental health services</td>
<td>ESOL in a supportive, flexible atmosphere</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support for Pakistani woman in Keighley experiencing domestic violence</td>
<td>Staying Put Roshni Ghar</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
10. Process and implementation

Diagram 1 (below) shows the framework in action, illustrating how it might be used as a tool for commissioners. The process begins with the commissioner encouraging or requiring providers to deliver outcomes around the 15 domains for BME service users, allowing for flexibility to accommodate individuals who want different outcomes. When the provider demonstrates their capacity to deliver outcomes across the matrix, they start to provide the service which is then monitored by using the scorecards with occasional spot-checks by community researchers. Areas of concern are discussed by commissioners and participants in the involvement 'wheel', reviews are carried out, findings discussed and commissioner decisions are explained to the community participants.

Diagram 2 illustrates how the matrix could also be used as a tool for service providers and practitioners. It shows how partner agencies may help with assessments and support from a community or specialist perspective. Regular reviews enable the service user to change the inputs and outcomes they want. Monitoring is required to maintain standards.
3. A recovery plan is developed, which is likely to include the use of individual budgets and/or access to partner agencies to help the service user achieve the outcomes.

4. Feedback on the assessment process, services provided and progress towards achieving selected outcomes is reviewed regularly using the scorecard until the service user is discharged. Providers explore the reasons for any short-comings identified and seek to address them.

5. There may be a review of inputs and outcomes and new choices made, in which case, steps 2 and 3 may be repeated.

1. The service user reflects on his or her difficulties with the MH practitioner and decides which problem areas/domains he or she wishes to prioritise in the journey to recovery.

2. The service user is helped to explore his or her problems in some depth and to clarify the outcomes and inputs required, with a person s/he trusts and who understands his or her background. This may be a MH practitioner, but may also involve another agency (e.g. an agency focused on the needs of a particular community or people in a particular situation such as domestic violence or asylum seeker).

Implementation

Commissioners

Commissioners and their partners can use the matrix and scorecards as a guide to service development, encouraging and in time requiring local providers to deliver the preferred outcomes. They can guide investment in the service economy. The matrix gives commissioners a remit to engage with clinicians on the value and scope of alternatives to a medical approach. Commissioners can use the measures within the framework to monitor and review the capacity of any publicly funded agency to deliver what is required.

Service managers

Service managers who want to improve support for BME service users can use the matrix as a guide to service development. They can ensure practitioners have the training, supervision and information which enable them to work in partnership with third sector agencies. They can encourage and allow practitioners to give the extra time needed to carry out joint assessments and partnership working. They can encourage clinicians, psychiatrists and GPs to take on board service users’ choices and activities. By developing self directed care, they can increase the flexibility of support.
Practitioners

This example illustrates how a young Bangladeshi man might be supported by his practitioner to pursue his goals for recovery:

A practitioner decides to carry out an assessment together with a partner agency and the young man is able to explore his problems with reference to his cultural, spiritual and social values. He identifies the outcomes he wants: paid work and financial independence. To achieve this he says he needs spiritual support within his Muslim faith, a trusted person to talk to from his community, light physical exercise, peer support, vocational support and medication which does not hinder an active lifestyle. He is isolated from his community due to the stigma of mental ill-health. The practitioner liaises closely with one or more third sector agencies (e.g. Sharing Voices, Bangladeshi Youth Organisation) and a specialist mental health employment advisor and ensures medication does not inhibit the young man’s activities. The third sector agency(ies) encourage the young man to join a peer support fitness group with other male BME mental health service users, link him with spiritual support from a visiting sheikh, and involve him in community development activities as a volunteer to build up his confidence and community connections (all these options are currently available from Sharing Voices). The mental health practitioner regularly liaises with the third sector project(s), which send staff to the young man’s care plan reviews.

Table 7 offers some suggestions on how to implement the framework across all domains.

Table 7  How to implement the framework: suggestions across all domains

<table>
<thead>
<tr>
<th>LEVEL</th>
<th>SUGGESTIONS OF HOW TO</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMMISSIONING</td>
<td>Engage in dialogue with providers about how the framework might be used in their work and use it to show the direction in which the tPCT wishes services to develop.</td>
</tr>
<tr>
<td></td>
<td>Engage with clinicians about using a range of alternatives to medication.</td>
</tr>
<tr>
<td></td>
<td>Pilot the framework; we suggest pilot areas include the Crisis Resolution, Forensic Services and a community organisation e.g. Sharing Voices; put in place an evaluation using action research principles from the start.</td>
</tr>
<tr>
<td></td>
<td>Implement the indicators based on the service user perspective and use them as levers to change. Similarly use monitoring data and qualitative reviews, ensuring people from BME communities are involved as reviewers (with appropriate support).</td>
</tr>
<tr>
<td></td>
<td>Arrange a mapping and review of the local service economy to find out the gaps in local services. Require providers to use the scorecard of community resources. Invest to fill the gaps.</td>
</tr>
<tr>
<td></td>
<td>Implement the BME involvement strategy to co-design services and improve feedback.</td>
</tr>
<tr>
<td>SERVICE/ORGANISATION</td>
<td>Develop partnerships between practitioners and the voluntary/community sector; ensure team leaders/supervisors encourage and support partnership working. Ensure staff have information about local resources, agencies and educational opportunities. Support implementation of the framework by developing assessment tools/forms and training.</td>
</tr>
<tr>
<td></td>
<td>Ensure staff are confident in offering and enabling their service users to benefit from individual budgets. Managers review service user feedback at quarterly and/or six monthly intervals and use to re-design services. Encourage peer learning across the teams. Support the BME involvement strategy to co-design services and improve feedback.</td>
</tr>
<tr>
<td>PRACTITIONER</td>
<td>Get regular feedback from BME service users through the scorecard and use it for personal development, to improve skills and approach. Develop partnership skills and relationships; acquire a good knowledge of local resources; work closely with partner agencies and ensure good coordination of support for individuals. Make use of individual budgets for flexibility.</td>
</tr>
</tbody>
</table>
11. Domains in more detail

The tables below describe how each group in the research interpreted key domains that were relevant to them. Tables 8 - 11 cover family, spirituality, work/worthwhile activity and community/social relationships. Tables 12 - 14 cover safe spaces/trusted person, mutual support and appropriate healthcare. These tables are followed with notes from community consultations on work, spirituality and individual budgets. Individuals may vary and will not necessarily want the same outcomes as others from their community.

Table 8 Family

<table>
<thead>
<tr>
<th>GROUP</th>
<th>WHAT THEY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYPSY AND TRAVELLER WOMEN</td>
<td>The family was said to be the central source of support and purpose. Elders are respected and cared for by their extended family. Travelling is a way of keeping in touch with the family. Many adults do not read or write and rely on children/grandchildren to help. Sometimes they want access to confidential help outside the family.</td>
</tr>
<tr>
<td>AFRICAN MEN</td>
<td>Individual self respect and wellbeing were said to be closely linked to men’s ability to maintain positive roles in the family, especially as breadwinner, but discrimination in the job market can prevent them fulfilling these roles. Young people born in the UK may have different attitudes and values to parents which can be a source of tension.</td>
</tr>
<tr>
<td>POLISH PEOPLE</td>
<td>Older Polish people increasingly suffer from bereavement of their spouse and isolation. Family carers can feel under pressure. Migrant workers may be separated from their families but increasing numbers are bringing them to the UK. Economic pressures, lack of English language and isolation threaten the wellbeing of migrant families.</td>
</tr>
<tr>
<td>AFRICAN CARIBBEAN PEOPLE</td>
<td>Elders may have the benefit of family carers, who can feel under pressure to meet their needs. Attitudes and cultural values may differ with each generation born in the UK. Young people said role models and support from the extended family were important. Young men experienced considerable racism in institutions and in the community.</td>
</tr>
<tr>
<td>SOUTH ASIAN WOMEN</td>
<td>Some women leave their family behind in Pakistan and feel isolated in the UK, with loneliness exacerbated by poor marital relationships. Children’s welfare is the focus for many women, and family support is crucial in poor health. Some women would also like more opportunity for education and work, but NHS staff tend to expect the women to remain in the home.</td>
</tr>
<tr>
<td>SOUTH ASIAN MEN</td>
<td>Men felt a strong responsibility to provide financial support for their family, which could create a lot of pressure. The men we consulted spoke of the importance of good marital relationships, respect and consideration in the home to help them cope with life. The men often had considerable control over the women’s activities outside the home.</td>
</tr>
<tr>
<td>MUSLIM WOMEN WITH EXPERIENCE OF DOMESTIC VIOLENCE</td>
<td>Children often provided the motivation to survive or get out of the situation. In-laws exacerbated or even caused the problems and could prevent the women from telling others or getting help. The woman’s own family were not always able to help. The woman may not be able to tell them or wish to tell them.</td>
</tr>
<tr>
<td>ASYLUM SEEKERS AND REFUGEES</td>
<td>Families could be split during their flight to the UK or on arrival, causing immense distress. Cramped housing conditions and lack of basic resources made life at home very difficult.</td>
</tr>
<tr>
<td>MALE AFRICAN &amp; ASIAN SERVICE USERS</td>
<td>Families could be the major source of support but could also be a source of tension and distress. Support staff who understood the cultural and family background were said to be important.</td>
</tr>
</tbody>
</table>
### SPIRITUALITY

<table>
<thead>
<tr>
<th>GROUP</th>
<th>WHAT THEY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYPSY AND TRAVELLER WOMEN</td>
<td>Some like to go to the Gypsy and Traveller churches, e.g. in Wakefield, others pray at home. Spirituality and practicing their Anglican or Catholic faith can be very important to their wellbeing.</td>
</tr>
<tr>
<td>AFRICAN MEN</td>
<td>Many African men feel that emotional and spiritual support are linked, and they value community-led approaches to support which can provide mental health support with a spiritual and cultural understanding. Younger men may attach less importance to spiritual support.</td>
</tr>
<tr>
<td>POLISH PEOPLE</td>
<td>The Polish Catholic church brings people, especially elders, together for spiritual and social support. Some migrants and younger people may not have a close connection with the Church, but remain spiritual.</td>
</tr>
<tr>
<td>AFRICAN CARIBBEAN PEOPLE</td>
<td>Caribbean elders often get a great deal of strength and support from their church, especially the Black led churches they have helped to establish. Their adult children may attach more importance to personal values about how they should live and develop their own notions of spirituality. Young people may be more variable in their spirituality. Increasing numbers are joining the Muslim faith. Spiritual support can be very important when people are unwell.</td>
</tr>
<tr>
<td>SOUTH ASIAN WOMEN</td>
<td>South Asian women spoke of the immense value of spiritual support in times of difficulty, but not all wanted to get this in the same way. Some preferred to learn about spiritual matters from other women, e.g. in peer groups. Some spoke of praying or reading the Quran alone or with others, or of speaking to a Sheikh about their problems. Help with spiritual support on the mental health wards is currently lacking and not integrated into care plans but would make a positive difference to many women.</td>
</tr>
<tr>
<td>SOUTH ASIAN MEN</td>
<td>Spiritual support was as important to young Bangladeshi men as it was to the elders. They spoke of talking to the imam, scholar or mosque teacher, to share their problems about any aspect of life and get some guidance. The men said prayers before activities at their community centre; spirituality and faith form an integral part of their lives. However, it was suggested that mosques and imams vary in the interest they show or attention they give to personal, family and social issues.</td>
</tr>
<tr>
<td>MUSLIM WOMEN WITH EXPERIENCE OF DOMESTIC VIOLENCE</td>
<td>Spiritual support, practice and belief in their faith helped the women to survive their situation. They distinguished between Islam, which respects the woman, and cultural practices which condone domestic violence. It was felt that religious leaders could play a major role in addressing domestic violence, but often did not do so (see above).</td>
</tr>
<tr>
<td>ASYLUM SEEKERS AND REFUGEES</td>
<td>Spirituality may be important for some asylum seekers but not for others. Access to spiritual support was said to be helpful. Some practiced their faith alone.</td>
</tr>
<tr>
<td>MALE AFRICAN &amp; ASIAN SERVICE USERS</td>
<td>Mental health services were felt to cater poorly for people with spiritual needs. As a secular service, some felt it lacked the most important ingredient for support. Prayer facilities on the wards were said to be poor on the whole. Expert advisors felt that the chaplaincy on mental health wards could play a much greater role in helping people.</td>
</tr>
</tbody>
</table>
### Table 10 Work and worthwhile activity

<table>
<thead>
<tr>
<th>GROUP</th>
<th>WHAT THEY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYPSY AND TRAVELLER WOMEN</td>
<td>Some would like more educational support for children who leave school at 11, so they can get the qualifications they need for good jobs. Qualifications are now needed for many jobs traditionally done by Gypsies and Travellers, making a good education more important than in the past. Access to work can be hampered by difficulties in travelling.</td>
</tr>
<tr>
<td>AFRICAN MEN</td>
<td>The men spoke of racism and discrimination in the workplace and in the job market, which made it hard to get work, hard to get promotion and could lead to bullying or harassment at work. Many African cultures attach immense value to the male breadwinner role and money brings respect, so joblessness can severely impact on the family and self respect.</td>
</tr>
<tr>
<td>POLISH PEOPLE</td>
<td>Migrants want information and advice on job opportunities and rights. Some cannot use their qualifications in the UK and want these transferred more easily. Action is needed to tackle exploitative employers. Joblessness can quickly lead to a crisis and mental ill-health, but some are reluctant to return home having apparently ‘failed’ where others succeeded. Poles of all ages are often dedicated to helping others in their community: they are a resource to develop and support.</td>
</tr>
<tr>
<td>AFRICAN CARIBBEAN PEOPLE</td>
<td>Men especially found racism and discrimination a major issue across all spheres of life. Racism at school had a detrimental impact on education and therefore on employment opportunities. Racism can have a severe impact on mental health. It was said that women find it easier to negotiate ways around racism both at school and in the workplace.</td>
</tr>
<tr>
<td>SOUTH ASIAN WOMEN</td>
<td>Women wanted to learn English and take up other classes including training for work, but it can be too expensive. They enjoy learning with others at peer support/community groups. Heavy medication, e.g. depot injections, low expectations and lack of childcare are barriers to learning. Voluntary work can appeal, e.g. helping at school and in the community.</td>
</tr>
<tr>
<td>SOUTH ASIAN MEN</td>
<td>Young men seemed anxious about getting the right help to find a job and earn enough money to buy a house. Older men put a lot of emphasis on their family and community roles, and the difficulty of managing on an ‘ordinary worker’s’ job.</td>
</tr>
<tr>
<td>MUSLIM WOMEN WITH EXPERIENCE OF DOMESTIC VIOLENCE</td>
<td>Most women were tied to the home with small children. While experiencing violence, it was difficult to do more than survive. One woman chose to remain in the home but found ways to get out during the day, taking up learning and community activities. After getting out from the violent situation, women wanted opportunities for personal development, learning and work.</td>
</tr>
<tr>
<td>ASYLUM SEEKERS AND REFUGEES</td>
<td>They wanted English language tuition, other vocational and leisure classes, voluntary and community work opportunities with expenses and childcare paid, while claiming asylum and until having the right to work. Schemes to train and organise volunteers from the asylum seeker/refugee groups would provide a valuable resource helping to provide peer support to others.</td>
</tr>
<tr>
<td>MALE AFRICAN &amp; ASIAN SERVICE USERS</td>
<td>Having a worthwhile role helps the men to get out of bed in the morning and gave a sense of purpose. Help to work towards employment was wanted, including access to education. Benefits advice in relation to work, education and training is crucial.</td>
</tr>
</tbody>
</table>

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30
OUTCOMES AND COMMISSIONING PROJECT
Table 11  Community and social relationships

<table>
<thead>
<tr>
<th>GROUP</th>
<th>WHAT THEY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GYPSY AND TRAVELLER WOMEN</strong></td>
<td>A sense of community is very strong among Gypsies and Travellers. Many want to live on the sites to maintain links. Households wanted fencing around their own caravan plot, to provide safety for elders and children. Some wanted places for young people on the sites to come together socially or to do their homework, as in Wakefield.</td>
</tr>
<tr>
<td><strong>AFRICAN MEN</strong></td>
<td>The notion of ‘I am my brother’s keeper’ or the Swahili concept ‘Ujamaa’ is important to many African people: this describes the sense of responsibility they feel to the wider community, beyond their extended family, and clashes with Western individualism. Community activities led by one African organisation promoted integration.</td>
</tr>
<tr>
<td><strong>POLISH PEOPLE</strong></td>
<td>Many elderly people remain isolated, sometimes traumatised by memories of atrocities during the war. Most have spoken little or not at all about these events to ‘outsiders’. Support from those who speak their language and understand their past is essential. The Polish Community Centre is an important resource bringing people together, but some Polish elders prefer to stay apart. They, and migrant workers, are often isolated and depressed.</td>
</tr>
<tr>
<td><strong>AFRICAN CARIBBEAN PEOPLE</strong></td>
<td>Many elders enjoy coming together with others to eat traditional Caribbean food and talk of past times while young people said that as long as their support workers/community centres respected them and made them feel at ease, a mixed environment was preferred. Places where African Caribbean people used to come together in Bradford are now gone. Young people were on the streets without an acceptable place to go, moved on by police. Spending time with others, having fun and a good laugh were extremely important across the generations.</td>
</tr>
<tr>
<td><strong>SOUTH ASIAN WOMEN</strong></td>
<td>For the women who have been isolated and depressed, getting friendship through peer groups or community development activity or learning made a real difference to their lives. Groups of women came together in community projects like Roshni Ghar and Sharing Voices and community centres. Having fun and learning together was said to be extremely important, helping them recover after a period of ill-health or distress.</td>
</tr>
<tr>
<td><strong>SOUTH ASIAN MEN</strong></td>
<td>Both young and older men spoke of the importance of community centres, the importance of integration, and the presence of racism. Older men valued contributing to community activities for their peers.</td>
</tr>
<tr>
<td><strong>MUSLIM WOMEN WITH EXPERIENCE OF DOMESTIC VIOLENCE</strong></td>
<td>Most women were totally isolated and generally unable to share their problems with others, but once they were out of danger and began the process of recovery, they started to build up a network of social relationships within the community which was extremely important to them. Setting up and/or attending peer groups made a huge impact.</td>
</tr>
<tr>
<td><strong>ASYLUM SEEKERS AND REFUGEES</strong></td>
<td>Some asylum seekers spoke of the harassment and hostility in the area where they were housed by the local authority. Some wanted to learn English so that they could integrate better, but this has become too expensive.</td>
</tr>
<tr>
<td><strong>MALE AFRICAN &amp; ASIAN SERVICE USERS</strong></td>
<td>Some felt that providing peer support to other service users was the best form of worthwhile activity. Some experienced harassment from neighbours on account of their mental health problems. Having friends and social interaction were said to be one of the most important factors in restoring wellbeing.</td>
</tr>
</tbody>
</table>
Table 12  Safe spaces with a trusted person to talk to

<table>
<thead>
<tr>
<th>GROUP</th>
<th>WHAT THEY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYPSY AND TRAVELLER WOMEN</td>
<td>Many wanted a trusted person to act as an intermediary and advocate, easing access to practical help, emotional support and health services. This person should visit the site but also should be available at an off-site base for one to one support and advice. Some women but not all wanted this advisor to be from a Gypsy/Traveller background.</td>
</tr>
<tr>
<td>AFRICAN MEN</td>
<td>It was suggested that African pastors, elders and community workers visit wards to offer spiritual and general support. Elders are highly respected in African communities, but less so among younger, UK born African people. It was felt that a greater profile and more funding should be given to support African-led community support.</td>
</tr>
<tr>
<td>POLISH PEOPLE</td>
<td>Migrants want a central point where they can get information, advice and access emotional support in their own language. Like the established community, they want places where they can enjoy themselves and learn with their peers. Trusted people can include CDWs and Outreach workers speaking Polish and understanding mental health.</td>
</tr>
<tr>
<td>AFRICAN CARIBBEAN PEOPLE</td>
<td>Young people wanted youth or community workers with an understanding of mental health and sources of support in their own language. Like the established community, they want places where they can enjoy themselves and learn with their peers. Trusted people can include CDWs and Outreach workers speaking Polish and understanding mental health.</td>
</tr>
<tr>
<td>SOUTH ASIAN WOMEN</td>
<td>Women wanted non-stigmatising places to go where they feel safe and supported by youth workers/CDWs/other women, who speak their language, understand their situation and have an understanding of mental health and sources of support. They need to be sure that their confidence will not be broken and their words will not be repeated outside. Young people, adults with children and older women want groups where they can come together with their peers in such a place with these workers. This was their most important source of support.</td>
</tr>
<tr>
<td>SOUTH ASIAN MEN</td>
<td>Many want somewhere they can talk with their peers, learn and enjoy themselves in their own language and feel at ease, e.g. some community centres. Community development workers, who speak their language, understand their situation and have an understanding of mental health and sources of support to engage with on an informal basis.</td>
</tr>
<tr>
<td>MUSLIM WOMEN WITH EXPERIENCE OF DOMESTIC VIOLENCE</td>
<td>Women would benefit from information e.g. at GP surgery &amp; from health visitor, about how to find and speak to a trusted person in safety. They wanted confidential support from workers (specialist or community development) who understand their situation.</td>
</tr>
<tr>
<td>ASYLUM SEEKERS AND REFUGEES</td>
<td>Safety for asylum seekers is first and foremost escape from the violence and danger in their own country, but then they may feel insecure due to racist harassment in the area where they are housed and the immigration process. Talking with peers or with trusted advisors in settings where they feel comfortable and safe helps to maintain hope.</td>
</tr>
<tr>
<td>MALE AFRICAN &amp; ASIAN SERVICE USERS</td>
<td>Men may want informal, non-stigmatising settings where they feel respected and listened to by those who understand them, their heritage and values. Some felt staff in institutional mental health settings did not understand them.</td>
</tr>
</tbody>
</table>
### Table 13 Mutual support

<table>
<thead>
<tr>
<th>GROUP</th>
<th>WHAT THEY WANT</th>
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</thead>
<tbody>
<tr>
<td><strong>GYPSY AND TRAVELLER WOMEN</strong></td>
<td>A person with a Gypsy or Traveller heritage is preferred by some (not by all however) as a source of advice, advocate or intermediary. Families provide a great deal of support to each other, especially caring for their elders.</td>
</tr>
<tr>
<td><strong>AFRICAN MEN</strong></td>
<td>Many want community support services led by and for African people, to provide opportunities to come together as African people, especially the elderly, to eat African food and enjoy social activities together. Some current activities by an African project include friends who are not African, to promote understanding and integration.</td>
</tr>
<tr>
<td><strong>POLISH PEOPLE</strong></td>
<td>Many want funding, resources and training to build upon the skills and energy of Polish people committed to helping others in their community, both within the established and migrant population. They want a variety of ways of reaching people, i.e. established support structures, such as the Polish Club and new support structures.</td>
</tr>
<tr>
<td><strong>AFRICAN CARIBBEAN PEOPLE</strong></td>
<td>Elders had a strong organised network of mutual support through the church, keeping in touch and helping those who are ill. At Mary Seacole Court they provided informal support to each other, much as the adult women did in a health related activity group. Young men wanted help from workers who have shared similar experiences in life.</td>
</tr>
<tr>
<td><strong>SOUTH ASIAN WOMEN</strong></td>
<td>The women who came together in peer groups found this helped them recover from difficulties: something to look forward to, support which enabled them to see their life in a more positive way which gave them ideas of how to cope, and a source of friendship, learning and fun. People came from the wards and community to attend.</td>
</tr>
<tr>
<td><strong>SOUTH ASIAN MEN</strong></td>
<td>The older men said that when people with mental ill-health came to join their community social groups, they benefited greatly, opened up and felt better. They were keen to help those who were isolated or unwell. Young men needing help would go to community or faith leaders if in difficulties, to get help from within the community.</td>
</tr>
<tr>
<td><strong>MUSLIM WOMEN WITH EXPERIENCE OF DOMESTIC VIOLENCE</strong></td>
<td>After the women left the situation or it improved, they took up the opportunity to give and receive support with others with similar experiences. They found this extremely beneficial to their wellbeing and rewarding for those who gave to others, and made a major contribution to their personal recovery.</td>
</tr>
<tr>
<td><strong>ASYLUM SEEKERS AND REFUGEES</strong></td>
<td>Asylum seekers and refugees valued receiving support and advice from others who have similar experiences. These were said to have a much greater understanding than others.</td>
</tr>
<tr>
<td><strong>MALE AFRICAN &amp; ASIAN SERVICE USERS</strong></td>
<td>Providing and receiving support from other service users was said to be a particularly valuable kind of help when experiencing mental health difficulties. They inspire hope and understand the problems.</td>
</tr>
</tbody>
</table>
### Table 14 Appropriate physical and mental health care

<table>
<thead>
<tr>
<th>GROUP</th>
<th>WHAT THEY WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>GYPSY AND TRAVELLER WOMEN</td>
<td>They wanted respectful NHS staff who have an understanding of their background and lifestyle: GP surgery reception staff were sometimes severely lacking in this. Also bereavement counselling that takes account of their values. Access to healthcare from GPs as they travel, e.g. some mechanism for the transfer of case notes. GPs, hospitals and mental health services sometimes failed to provide accessible information or recognise carer’s needs.</td>
</tr>
<tr>
<td>AFRICAN MEN</td>
<td>Emotional/mental health support that takes on board their spiritual needs. Visits from pastors or others for people in hospital. Community led support for those leaving hospital. Recognition of the specific needs of African people. An increase of public awareness of mental health and sources of support among the African community.</td>
</tr>
<tr>
<td>POLISH PEOPLE</td>
<td>Alternatives to medication. Polish speaking emotional support, talking therapies, bereavement counselling, memory testing. Social prescribing. Peer support and home visiting. Information for migrants about how to get access to health services. Help for carers. NHS staff understanding the social, economic and cultural pressures on migrants and the established elders, more outreach, CDWs and Polish speaking PALS.</td>
</tr>
<tr>
<td>AFRICAN CARIBBEAN PEOPLE</td>
<td>Some want alternatives to medication, such as talking therapies, bereavement counselling and health related activities. Adult women had a reluctance to go to the GP for fear of being given medication. Those caring for elders needed more support. Some elders felt that they did not get enough help from health or social care services.</td>
</tr>
<tr>
<td>SOUTH ASIAN WOMEN</td>
<td>Some wanted alternatives to medication, e.g. spiritual support, peer support and activities. Some felt that they have been on medication for too long and wanted more information about side effects. They want nurses and doctors to have a better understanding of their cultural and spiritual needs, and they wanted the doctors to make it easier for the women to talk to them about their health. Some said services had low expectations of South Asian women.</td>
</tr>
<tr>
<td>SOUTH ASIAN MEN</td>
<td>The older men wanted an efficient response to their physical health problems and a flexible response to their emotional needs. The younger men appeared to know little about what emotional help is available from the NHS.</td>
</tr>
<tr>
<td>MUSLIM WOMEN WITH EXPERIENCE OF DOMESTIC VIOLENCE</td>
<td>GPs seeing women experiencing violence prescribed medication, not realising their situation. The women felt GPs should learn how to recognise the signs of domestic violence, be able to make enquiries if suspicious and know of voluntary sector projects able to offer support. GPs are likely to be the only professional that the woman sees. GPs should have access to interpreters for female patients and not allow relatives to be present in the interview room. Women wanted alternatives to medication prior to and after leaving the abuse.</td>
</tr>
<tr>
<td>ASYLUM SEEKERS AND REFUGEES</td>
<td>Access to healthcare was the greatest issue for asylum seekers and refugees. Several received medication for their emotional distress and depression but on the whole did not find it helpful. Access to physical healthcare could be very limited or slow.</td>
</tr>
<tr>
<td>MALE AFRICAN &amp; ASIAN SERVICE USERS</td>
<td>Some wanted alternatives to medication. Some felt that once admitted to mental health services, it could take a very long time before they were given effective help to recover. Mental health services lacked spiritual support.</td>
</tr>
</tbody>
</table>
Community consultation: Employment and Worthwhile Activity

Worthwhile activities: what do we want?

A worthwhile activity has some or all of the following features:

- It makes a difference to us and/or others.
- It takes our mind off our own problems.
- It motivates us, gets us out of bed, gives us purpose.
- It makes us feel valued, confident, better in ourselves.
- It is fun, involves doing things together with others, having a laugh.
- It involves taking exercise, getting out and about.
- It helps with our career and aspirations, gives accredited learning.
- It breaks down barriers between communities, and
- It strengthens our sense of identity, faith and culture.
- We don’t have to worry about losing benefits and get expenses paid, e.g. childcare, travel.

Examples

- Community work, providing peer support, mentoring, NHS involvement.
- Trips bring people together to explore new places.
- Arts: dancing, singing, cinema, writing, sewing with others.
- Learning of all kinds: new roles/tasks, accredited study, English language, cooking.
- Activities for one gender/cultural group and activities involving diverse groups.

What makes it possible?

- Informed choice: information about a range of options and able to choose freely.
- Finance: expenses paid and good advice on implications for benefits.
- Support and encouragement: Lots of it, especially from mental health/support worker and those organising the activity.
- Safe space: it takes place with trusted people in a known or non-stigmatising venue.
- CPA support: practitioners encourage worthwhile activities from admission onwards.

Employment: what do we want?

The employment we want has some or all of the following features:

- Full time, part time and sessional work opportunities are all valued.
- A workplace respecting diversity and disability/mental ill-health where we feel safe.
- A job which reflects my skills and helps to develop my potential.
- A job which gives me confidence – and doesn’t undermine it.
- Job satisfaction – a job which makes a difference to others.
- Support – mental health support outside the workplace, management support within it.
- A supportive and friendly team of colleagues.
- Flexibility and facilities regarding faith, health and dependents.
- Pay which makes it worthwhile.
- Some might like a job in a social firm/enterprise with others who have used mental health services.

What makes it possible to get and keep a job?

- A care plan which takes account of what I want to achieve.
- Someone with a cultural connection or understanding who gets my trust, e.g. through outreach, gets me active and hopeful.
- An employment support worker who is:
  - Supportive, friendly, understanding, encouraging.
  - Respectful not patronising, treats me as an equal.
  - Informal, not bureaucratic. Creative and flexible.
  - Able to listen to what I want as a goal and what help I want to achieve it.
  - Able to liaise with employers and check out the workplace for discrimination.
- Help to address practical problems with the transfer into work.
- Help with the financial difficulties during the transfer into work, including getting my full entitlements from the benefit system.

What can commissioners do regarding worthwhile activity and work?

- Require mental health and social care service providers to help service users of all ages explore their interest in worthwhile activity or paid work at the first and
subsequent assessments and put in place support needed to pursue aspirations.

- Require funded mental health provider organisations to employ people of diverse ethnicity and with experience of mental ill-health at all levels in their organisation.
- Encourage community organisations funded by the tPCT to run organised volunteer schemes, run according to current good practice covering insurance, training, support and supervision, volunteer costs etc. (guidance available from Volunteering England www.volunteering.org.uk) - funded and monitored appropriately.
- Require funded employment/volunteer support schemes to monitor client ethnicity.
- Commission the CAB or other independent agency to provide work-related benefits advice to people with mental health problems, both in hospital and in the community.
- Commission specialist mental health employment support services with reference to current government guidance (CSIP, 2006b) and good practice (SCMH, 2008).

Community consultation: Spirituality

What do we mean when we talk about spirituality?

There are spiritual activities:
- There are different activities for different faiths, e.g. prayer, zigger, contemplation, religious studies, recitation, reading holy book.
- There are different activities for different individuals, e.g. eating together, moral activities, or it may be something about the way we behave and feel together.
- It can be where people come together with others of the same faith.
- It can involve reflection or contemplation in retreat, on our own.
- It can involve walking, being close to nature.

There can be a spiritual connection:
- With our own inner self, with nature, with a bigger power/presence, with other people.
- It may involve reaching out to others.
- There may be a sense of belonging – with others, with a place.

It can be a group or individual way of moving towards peace and tranquillity within; a journey towards wisdom and understanding, arriving at a better perspective feeling stronger.
- Can be to do with faith or nature or something else.
- Can be a process of cleansing in body and mind, moving towards purity.
- It is what the individual says it is – only they can say what gives them this feeling.
- We may need to study and search to make that journey.
- It can be journey towards self discovery – learning more about ourselves, what we are and what we want to be – it may be about bridging that gap.

It can give purpose or meaning to life.
- It can explain why we are here. It may give a sense that there is a purpose beyond our understanding.

It could be within us all (maybe before and after life on earth).
- We have to find it ourselves.
- We may come to it through our culture and upbringing, or through life events and/or questioning.
- We do not all come to realise it; we are not all encouraged or helped to realise it.

It is something we can’t explain. It is beyond the material. A wider definition allows more people to find a connection. It can be about a way of life.

It can do more for us than pills. But:
- It cannot be measured – it is intangible.
- It can have a big impact on the individual.
- It is usually dismissed in NHS. It can be regarded as evidence of delusions. It is rarely discussed at CPA meetings.
- Mental health practitioners often lack the resources to meet spiritual needs.
- It can be described as ‘Medicine for the soul’ ‘Lightens the burden’ ‘Taps into human power to heal’.

How can you tell that someone’s spiritual needs have been met?

What do you ask the service user?
Open questions not tick box.
“Have you been given the opportunity to explore what spirituality means to you – with a range of people, over time and in different settings?”
“Have you been given access to support and resources to explore spirituality?”
“Do you think your personal choices/values have been taken into consideration?”
“Have your carers been made aware of your spiritual needs?”
“What works for you?” in terms of spirituality.
“Were you asked about spirituality? Did you trust the worker and engage in that conversation?”
“Can you get to church/mosque etc” – do you have transport and the help you need.

What would count as evidence?
• Personal stories
• Evidence of insight gained (from perspective of staff, family or service user).

Where would spirituality and the effectiveness of spiritual support be explored?
• Integrate spirituality into all care planning and practitioner/service user meetings, ward rounds.
  Nurses can have a key liaison role.
• There would have to be a feeling that it is safe to talk about spirituality, so that individuals can talk freely (and not have their words interpreted in other ways by doctor). Staff and service users alike rarely feel safe to talk about spirituality in NHS.
• Advocates and/or family may be helpful.
• Trust is the key issue here. This discussion has to be done privately. Some people may need interpreters.
• There is a risk of leaving it all to the voluntary and community sector and not following it up – i.e. not a true partnership approach with VCS workers.
• The VCS and faith groups may have a better understanding of the person than statutory workers can ever do.

Workforce issues
• Both staff and service users need to feel empowered before spirituality is fully recognised in mental health services.
• Senior management in NHS need to become more aware. Staff need training.
• Chaplains and other faith leaders need training in mental health.
• Partnership working needs to improve.
• Spirituality needs to become integrated within care planning processes.

What can commissioners do regarding spirituality?
• Require mental health and social care service providers to help service users of all ages explore spiritual issues, in particular what spiritual support they may want and put in place the support they want at their first and subsequent assessments.
• Require mental health and social care service providers to train staff in spirituality relating to mental health, develop the role and profile of the chaplaincy at BDCT and recognise the importance of spirituality in the provision of mental health services.
• Monitor and evaluate the success of provider agencies in enabling service users to get the spiritual support they need.
• Investigate ways in which spiritual support may be provided safely for people with mental health problems in the community; fund and monitor to meet different needs.
• Promote and monitor partnership working between mental health/social care providers and spiritual support services.

Community consultation: Direct payments and individual budgets

What do we like about the idea of direct payments/individual budgets?
• Service users have more say over their own services.
  - They have more choice and control.
  - They share decision making power with doctors and professional staff.
  - The expertise of the service user is being recognised.
• This process itself has a beneficial impact on the service user:
  - They get confidence, they gain power and control – so feel empowered.
  - They take responsibility for their own care and so will be motivated to self-manage their health issues.
  - They become more aware of their civil and legal rights.
• Care provided can be more flexible, varied and innovative:
  - It can include help with jobs, housing, visits to family, shopping, gym, alternative therapies, spiritual healing, massage.
  - It can cater for people with different value systems /different understandings.
  - It can provide help of the right kind when and where it is needed.
- It will promote independent living.
- It will provide more variety at less cost – so be cost effective.
- It can alleviate service user frustration because they feel they are being listened to.
- By tracking the way people are spending the money, direct payments/individual budgets will inform and influence service development – it will show what works for whom in what context.
- It will increase awareness of the diversity in community groups – and the diversity of what works for different groups.

**What are the challenges and risks?**

- How can we be sure the assessment of support needs is fair and does not replicate existing institutional inequalities for people from BME communities?
  - The service user gets money to meet the needs identified in their care plan or support plan – but what if the professionals (GP, psychiatrist, staff) don’t understand what the service user needs? What if they won’t listen?
  - How do we make sure they recognise gender, faith and ethnicity issues?
  - How do we get professionals to recognise an individual’s strengths instead of focusing on their difficulties?
  - Will there be advocates in assessments and reviews?
- How will the review process work? Who will make the decisions?
  - How will it get the right balance between making people dependent and encouraging them to move on?
  - What will happen if the money is suddenly cut off because the service user seems better, but then the service user can’t access the services that made him or her well – and a relapse is likely?
- Basically, to avoid replicating and perpetuating institutional discrimination and inequality, there needs to be:
  - a HUGE change in attitudes among professionals, including GPs, psychiatrists and staff. The attitudes of GPs and their gate-keeping role were a major concern.
- Steps must be taken to overcome language barriers.
- Effective help for the service user to negotiate during assessments and reviews.
- Good information and advice services for the service user about their options.
- What can we do for those people who won’t go to the GP?
- How will service users be made aware of what’s on offer, their rights and options?
  - Will there be an independent service telling them about this? It was felt that independence is ESSENTIAL.
  - If not, will staff (NHS or VCS) have a vested interest in their own services, and therefore not be impartial?
  - Will service users have loyalties to the staff in services they already use, and so find it difficult to move to different options?
  - Will the staff offering information about options have the time and expertise to advise different groups of people, including people with mental health problems from different communities?
- What about carers?
  - How much influence will they have in the assessment of support needs?
  - What help can they get through this system?
  - If the carer is managing the money, how will the service users’ interests be safeguarded? How can we be sure there is no abuse of power?
- The services people want may not exist. E.g. effective employment support for people with mental health problems. Will direct payments/individual budgets be used to pay for services that the NHS should provide anyway, like interpreting?
- What can be done to reduce the risk of tension and competition between the voluntary and community agencies in Bradford?
- What support will be provided to help people manage their money? If so, how much money will they take from the service user, in order to provide this support? Will the support cater for people from different communities with different health issues? Will it be a very bureaucratic process, with lots of delays and hoops to jump through?
- How can this tool be used to improve services for asylum seekers?
• How can we show the NHS what has really worked? How can we show that the service purchased through direct payments/IB is what has made a person better?

What can commissioners do regarding direct payments?

• Involve mental health BME service users and carers in the design and regular review of processes for individual budgets.
• Require mental health service providers to offer individual budgets wherever possible to promote choice for their service users and ensure their staff are fully trained on the scope and implementation of individual budgets.
• Ensure those in a position to offer and administer individual budgets are trained in race equality and mental health issues and ensure they have access to support and advice on these issues should they need it in the course of their work.
• Explore the scope for independent advice and advocates speaking different languages for those interested in individual budgets.
• Monitor and evaluate the use of individual budgets for mental health service users and carers from BME communities.
Part Four: **Strategy of Involvement**

“The BME Involvement Wheel”

What this strategy is about

This part of the report describes how and why voices of people from BME communities have been largely unheard by commissioners and providers, before proposing how these voices could be brought into mainstream and targeted processes for involvement. It sets out the advantages from the perspective of the tPCT in terms of greater satisfaction with services and greater compliance with government policy. After giving the rationale for the strategy we describe the BME Involvement Wheel: its purpose, structure, activities, accountability, and estimated cost. Finally we suggest a development phase for the immediate future.

**Diagram 3 BME Involvement Wheel**

Provided by Sasha Bhat
12. Background

What do we mean by ‘involvement’?

The legislation which sets out the duty to make arrangements for involvement is not prescriptive about what constitutes ‘involvement’ (DH, 2006, 2007). DH statutory guidance published in October 2008, *Real Involvement*, states that involvement covers a ‘spectrum’ of activities, including engagement of seldom heard communities, giving or getting information, consultations, public participation in service planning, reviews and co-designing of services. This strategy covers all these activities with a broad definition:

Service ‘user involvement’ can be defined as the active engagement of people who use mental health services in the development of mental health policy and practice, for example in the planning, delivery and monitoring of mental health services, in the training and education of mental health staff and in mental health research. (Trivedi, 2008)

Who will be ‘involved’?

The strategy complies with statutory guidance by including service users, carers and the wider community, including those who are not using services now but may do so in future.

‘Users’ includes people who are ‘easy to overlook’ and those who do not access services, despite having a need. (DH, 2008a)

It will draw in the views of smaller, new or rarely involved groups such as Gypsies and Travellers, new migrants, asylum seekers and refugees as well as sub-groups within the South Asian population and other minorities. It will seek the views of smaller groups within the Pakistani population, as recommended in a recent study by the Joseph Rowntree Foundation in Bradford (Blakey et al, 2006).

Past initiatives for BME service user/community involvement in Bradford

In 2006, a series of workshops brought together senior staff from BDCT, three of the local PCTs, Sharing Voices Bradford and Bradford University to explore issues of BME participation in mental health services. Their conclusions and recommendations, set out in the report *Participation Why Bother?* (Blakey et al, 2005), guide this strategy. They confirm there is no ‘quick fix’ to effective BME involvement, which challenges both the NHS and local communities: a commitment to start the process and learn as it progresses is the best way to start. Key points from the report include:

- A two way dialogue between communities and senior staff is required.
- People need a variety of ways to participate, including contributing as a group.
- Trusted organisations and workers are required to mediate and advocate.
- Communication channels can build on existing networks and meeting places.
- There need to be more opportunities for NHS staff to reflect openly on participation, its value and how to solve the difficulties that arise.

BDCT appointed a Social Inclusion and Participation Worker as a result of the work, but the commitment to *Participation Why Bother?* was not maintained, perhaps due to local reorganisations.

Sharing Voices also supported a *Mutual Interest Group* which had the potential to develop service user involvement, but this was not sustained after organisational changes. However, Sharing Voices has consistently enabled individual service users and carers to take part in involvement activities, taking up the opportunities that arise as they develop confidence in the project. These activities play an important role in the individuals’ recovery from mental ill-health and most individuals move on in due course to work or further/higher education. The opportunities for involvement, while important, are intermittent and often limited in scope.

Current involvement of BME communities in mental health commissioning

*Lack of proportionate involvement*

As we saw in Chapter 4, approximately a quarter of the population in the tPCT area has a BME heritage and the proportion is increasing. These figures suggest at least one in four of the people consulted by the tPCT should be from a BME background. The proportion of BDCT’s in-patients with a BME heritage is even higher, suggesting that at least one in three of the in-patients giving feedback should be from a BME background.

Instead, within mainstream structures for involvement, such as the *Service User Forum* or BDCT service user involvement activities, the number of people with a BME heritage is extremely low. No more than 4% of the responses to the 2008 Healthcare Commission’s *Community Mental Health*
Survey had a BME background. This compares with an 8% average across the country, showing Bradford and Airedale is performing poorly compared with other parts of the UK. Commissioners do not know if the services they fund meet the needs of between a quarter to a third or more of the people who use them.

Community engagement and consultation events

Feedback on existing participation suggests that BME involvement in service planning is primarily through ad hoc consultation or community engagement events. Local people have suggested that these would be useful if they were part of a broader structure for participation, but on their own they are inadequate:

- The agenda is determined by statutory authorities.
- There is little or no scope for a two way dialogue.
- The people involved are left ignorant as to whether they have had any impact on service design or delivery, leaving them disillusioned and sceptical about public participation. This reinforces the sense that participation is not taken seriously.

Formal participation on committees

There are opportunities for involvement in formal planning committees of various kinds, but these are rarely taken up and where they are, feedback has suggested that they do not offer a positive experience. Individuals have said that they feel demeaned by the process. There has been a lack of appropriate support, training and communication between participants and those organising meetings. Participants have had no way of knowing whether or not their views made any difference to service design or delivery, giving the impression that their involvement was tokenistic. These experiences echo the findings of Participation, Why Bother? (Blakey, 2005).

Failure to draw in smaller BME groups

There are many small community groups in Bradford who are rarely represented in any involvement activity, and the feedback we have received suggests they remain remote from BDCT, unlikely to ask for help until and unless they are in crisis. Examples include the growing population from Eastern Europe and Africa (ONS, 2008). At the same time, the number of ‘White Other’ in-patients has grown both locally and nationally. The fluidity of patterns of migration is such that the ethnic ‘mix’ in Bradford is constantly changing and participation structures have to be able to seek out and draw in new groups.

Participation ‘by proxy’

In many areas, tPCT commissioners and others seek the views of service users, carers and others from BME communities by proxy, from BME professionals working within the NHS or closely associated with it. It is unlikely that health professionals will accurately represent the views of those who use services, and this approach does nothing to improve the relationship between service users, local communities and mental health services.

Communications

Publicity about consultation activities is often sent out by e-mail at short notice. Many BME service users and carers do not have access to e-mail and many are unlikely to respond unless the information is received from and explained by a trusted source, face to face.

Practical issues

Activities and meetings often occur at times which are difficult for people with school age children. There is a lack of clarity and easy process for payment regarding childcare costs and attending tPCT meetings, for those who wish to be acknowledged in this way.

Trusted workers offering intensive support can increase participation

The DRE CDWs at Sharing Voices and Roshni Ghar are able to engage service users and others because they are perceived as ‘trusted people’ but this is done on an ad hoc basis due to the absence of a structure which enables service users and carers to work on a regular basis with the tPCT.

The Social Inclusion and Participation Worker within BDCT has supported participants within the Outcomes and Commissioning Project, enabling several people to participate in a way they would not or could not have done otherwise, but she has a short term contract and lacks the time or remit to support wider involvement for the tPCT.

It is easy to under-estimate the level and nature of support required to build up BME service users to take part in predominately white institutional settings where they are not accustomed to having a voice. This is extremely time consuming, skilled work carried out by Sharing Voices and Roshni Ghar when an opportunity arises to make an impact.
13. Integration not separation

Why do we need more than the local LINk?

The Local Involvement Network (LINk) is one but not the only mechanism whereby commissioners and others can involve local people. In Bradford and Airedale, the LINk takes a largely issue-based approach and does not have the resources or specialist expertise to support continuing involvement of service users and others from BME communities.

The purpose of this strategy is to bring in the necessary resources and expertise to engage and develop continuing involvement of BME service users and others, enabling them to actively engage with the LINk on issues of their concern.

The roles are therefore complementary, with the LINk and strategy of involvement helping each other to promote effective BME involvement.

The LINk is not there to replace wider involvement, it is there to promote it – it is one of the ways in which commissioners and other decision makers can access local opinion.

(DH, 2006)

Commissioners are expected to create a range of opportunities to involve users throughout the commissioning cycle. Working with the LINk is one way of obtaining their views, but should not be seen as the only way to involve users.

(DH, 2008a)

Why do we need a separate involvement strategy for the BME population?

Historical absence of BME groups in service user/carer involvement

Research has shown that the BME population has been notable by its absence in service user involvement structures across the UK (Wallcraft, 2003), and although CDWs are tackling the problem, there remains no evidence that significant numbers of BME service users engage in mainstream service user involvement processes anywhere in the UK.

Despite the importance given by the Department of Health to choice and involvement, user participation remains an ambition rather than a reality for black and minority ethnic users. However, black and minority ethnic user participation is key to improving the organisation and delivery of healthcare.

(Stuart, 2008)

Racism, stereotyping and disrespect

Our community research in Bradford and Airedale shows that the experience of racism, stereotyping and disrespect is a regular occurrence for many people from BME communities. These experiences are found in institutional settings (school, police and mental health services) as well as in the job market and neighbourhood life.

Within mental health services in the UK, BME service users can find the social inequalities they experience in daily life are exacerbated by being a patient with limited or no power (Trivedi, 2008).

These kinds of experience may deter people from getting involved because of:

- Fear or actual experience of disrespect within involvement settings.
- Feeling at a disadvantage in formal settings where the majority of participants are white, often better educated, better informed, formally dressed and more confident.
- Suspicion that involvement is required to ‘tick a box’ rather than to learn.
- Scepticism of the intention to change, as problems have been known for many years.
- Anger with service providers and commissioners.

Many similar but some different issues

While there are many concerns common to both white British and BME service users, there are important differences. BME groups may prioritise the experiences described above or issues relating to their culture. Our research shows that people from BME communities in the area understand mental health issues and the identification, presentation and solutions of mental ill-health in terms of their culture, faith, spirituality and social context. It is not possible to separate issues of mental health from their culture, spirituality or experience of being a person with a BME heritage in the UK.

Mental health services aim to be culturally competent and able to respond to the needs of people from different cultures. BME involvement can help them to achieve this, both in terms of practical issues such as food and prayer, and a
deeper understanding of the service users’ perspective, values and beliefs, and the nature of support they require.

Although these topics may attract empathy and interest from white British service users, it is unlikely that they will wish to give them the same priority as BME groups who regard them as of the utmost importance.

Stigma and unmet needs

It may be that BME service users do not get involved because many remain in an early stage of recovery with unmet basic needs (e.g. housing, health, financial, relationships) which have to take priority. Others who are in a better position may wish to move on to work or study, leaving behind their association with services because of the stigma and unhappy experiences within the system.

We believe that this strategy offers a way of engaging those with unmet needs and linking them more effectively to appropriate services. It also offers a forum for debate which will, we hope, open up mental health as a community concern and help to reduce stigma.

Integration for those supported, rooted in and accountable to their communities

Over the course of our project, we have found a strong desire among participants from different communities to work together across the BME population and with the white British population. However, this needs to be done with support, training and facilitation to make it a positive experience.

We also need to ensure that participants are well connected with and accountable to others from their community to improve local democracy.

A study carried out for the Joseph Rowntree Foundation recommended:

Create supportive forums for communities to come together outside statutory services, so that previously excluded groups can build their confidence and capacity to prepare for and participate in formal meetings. (Blakey et al, 2006)

In time this support may not be necessary, but for the foreseeable future, an integrated public and patient involvement process needs to build additional capacity, profile and connections among those most excluded.

Time and skills to gain the trust

As with all service user and carer involvement, a considerable amount of time and skill is needed to engage, support, encourage and organise participants who may have a chaotic lifestyle or be subject to sudden changes in circumstances. This work can only be done by a trusted person who has to earn credibility and trust over time, demonstrating their understanding of the individual’s background and concerns. Where there is no trusted support worker with this understanding, there will be little BME involvement. Workers supporting mainstream service user involvement often find it difficult to earn this trust.

The unique contribution of the BME Involvement Wheel

We have described this approach to BME involvement as a wheel because we think it describes the infrastructure and particular contribution well:

- At the centre (the hub) is the strength which holds the structure together: people from diverse backgrounds coming together for support, training, and involvement activities for a shared purpose.
- From all parts of the Bradford and Airedale area, individuals and groups based within voluntary sector or small community organisations are engaged with those at the centre. The specific skills of the worker and the BME ownership of the process will help to engage those seldom heard. Their views and responses pass to and fro (along the spokes), expressed by a spokesperson for the group or the worker from the centre. Accountability also flows to and fro from the centre to the groups.
- Facilitation sensitive to local tensions and community difference gives balance, ensuring the process enhances and does not hinder community cohesion.
- Involvement leads to response and change on a continuous, sustainable basis (movement of the wheel), replacing ad hoc, one-sided communication.
- There is movement of BME service users, carers and others to paid work and other roles in the community, as their health, skills and confidence increase.
- The community development approach provides the lubrication, building trust, drawing people in, enabling them to work together and when they wish, to move on.
- The shared learning within communities and tPCT steers the direction of change, reducing inequalities in mental health.
14. Business case: anticipated outcomes

The anticipated outcomes of implementing the strategy include:

- Higher levels of satisfaction among service users from BME communities, due to more culturally appropriate mental health and social care services based on better quality information.

- Evidence of world class commissioning and greater TpCT and local authority compliance with their statutory requirements relating to public participation.

- Increased involvement of people from BME communities in mainstream and service user participation activities, including research and staff training.

- Easy access for the TpCT to service users and others who can contribute to reviews, monitoring, staff training or equality impact assessments.

The strategy also offers ‘added value’ by leading to:

- Increased levels of recovery and therefore increased safety and reduced medication for service users from BME communities, due to their involvement in community activities. They can get involved, supported and trained from an early stage in their recovery, enabling them to move on in due course to education or work.

- Improved partnership working between the community, voluntary and statutory sectors by working with shared purpose and improved channels of communication.

- Reduced race inequality in mental health and social care services with
  - earlier access to help due to more trust and confidence in mental health services,
  - improved experience in mental health services due to more appropriate services,
  - improved outcomes as some BME service users recover earlier.

- Increased respect and understanding among diverse BME and white British communities, which will promote community cohesion and integration in Bradford. The strategy will increase BME involvement in both BME specific and mainstream public participation processes.

- Over time, cost benefits and more efficient services should accrue from the improved relationship between mental health and social care services and BME communities.

15. Purpose, structure, activities and accountability

Purpose of the BME Involvement Wheel

The purpose of this BME Involvement Wheel is to enable commissioners and others to involve BME communities, particularly service users and carers, in their work.

Activities

The BME Involvement Wheel can carry out a wide range of activities to achieve its aim of effective involvement, comprising: engaging, including, facilitating, training, supporting, connecting, giving and receiving feedback, carrying out research and review.

Engage individuals, groups and organisations

Use an outreach/community development approach and work with CDWs, community contacts, the voluntary and community sector and BDCT staff to:

- Identify individuals and groups with relevant interest and experience.
- Encourage and support their participation at the level of their choice.
- Develop good relationships and work alongside community and voluntary sector agencies with an interest in BME mental health issues.

Include unheard voices

Bring to the BME Involvement Wheel the views and concerns of the widest possible range of BME community interests by:

- Working alongside other community based workers in Bradford.
- Encouraging and supporting participants to attend BME Involvement Wheel workshops or meetings.
- Where local groups do not wish or are not able to attend, finding ways to bring their interests or concerns to the BME Involvement Wheel (e.g. through mapping, community spokespeople or CDWs).
**Facilitate debate and learning**

Facilitate respectful debate and shared learning among those who take part to:

- Promote respect for difference and awareness of shared values and concerns.
- Ensure that the interests of small groups or those not present are not overlooked.
- Explore issues of concern and agree priorities for change.

**Train local people and NHS staff**

Develop and coordinate training for people from BME communities which increase their:

- Knowledge of the NHS, its structure and services.
- Understanding of the opportunities and constraints for change.
- Confidence and skills for effective participation.

Contribute to the design and delivery of tPCT staff training programmes.

**Support participants**

Provide support and information to:

- Enable individuals to develop their skill and capacity for participation.
- Encourage individuals and groups to increase their level of participation over time.
- Enable individuals to access employment support or paid work when they wish.

**Connect and integrate**

Develop a network of contacts across the tPCT and the LINK [with the option of extending this to BDCT and the local authority] to:

- Enable commissioners and others to meet with the BME Involvement Wheel on a regular basis to exchange information and discuss concerns.
- In addition, enable commissioners and others to meet with the BME Involvement Wheel on an ‘as needed’ basis to discuss topics of particular concern, at the request of either the tPCT or the BME Involvement Wheel.
- Enable BME Involvement Wheel participants to take part in formal planning groups, committees and other formal involvement activities.
- Enable the LINK to identify the concerns of BME groups in relation to mental health and to work with the LINK to address these concerns.
- Encourage and enable BME Involvement Wheel participants to engage with other service user forums or networks and to arrange joint meetings about shared concerns.

**Feedback**

Facilitate a two way dialogue and exchange of information to:

- Enable the tPCT to report back to participants on the impact of their involvement activities and, where views have not led to change, to explain why not, in accordance with their statutory requirements.
- Enable Wheel participants engaging in formal committees and meetings to feedback on what happened and get a mandate for when they return to the committees.

**Research and outcome review**

- Liaise with academic support to plan and carry out small research projects to monitor community outcomes and satisfaction with services.
- Manage research training programmes, volunteers and community researchers.
- Respond to tPCT and community requests for reviews, needs assessments, impact assessments and other small research projects, if funded appropriately.

**The BME community participants**

The Wheel will engage and support people with a wide range of experiences, skills and interests who can get involved in different ways. We suggest that those actively taking part in involvement activities comprise approximately:

- One third with experience of using secondary mental health services.
- One third with experience of being a carer for a person with mental ill-health.
- One third with experience of distress but not necessarily experience of using support services, e.g. asylum seekers, refugees, people with experience of domestic abuse.

These proportions are similar to those in our project. We found that they worked well, with participants learning...
from and supporting each other. There may also be ‘associates’ - people working in mental health or BME community projects and services.

**Staffing: coordination, support, training and office base**

- One community development worker (senior), (0.6 FTE).
- Administrative support (0.2 FTE).
- Training programmes will be delivered by the Coordinator and, where specialist skills are required, sessional trainers.
- Academic support will be provided by a university or local freelance researcher with a track record in BME and mental health issues.
- Supervision and support for the Coordinator will be provided by the DRE CDW team.
- An office at a neutral community based venue - not identified with any community.

**Payment policy, expenses and refreshments for people taking part**

In line with DH recommendations, there will be a policy to cover:

- Payments for those attending Wheel meetings (approximately once a month).
- Payments to cover expenses for volunteers (childcare and travel).
- Refreshments at meetings.
- Payments for people contributing as participants in reviews and research activities.
- Payments for community researchers.

Payments will be at the rate determined by the tPCT policy for service user involvement.

**Accountability and constitution**

The Wheel will become an independent organisation with its own constitution, possibly in due course adopting a Community Interest Company structure. We recommend that this is not a social enterprise due to the inappropriate commercial pressure this puts upon service user involvement activities.

It will have a membership base and elected members of a management committee, which will include tPCT representation. Accountability will be to its members, the wider BME communities in Bradford and Airedale, and its funders the tPCT.

**Relationship of the BME Involvement Wheel with other BME organisations**

The DRE CDWs at Sharing Voices Bradford and Roshni Ghar engage service users, carers and others from BME communities and organise highly successful community engagement events. This strategy anticipates that they continue to engage local people in this way and hold community events. These form an essential part of their work.

The Wheel enables the tPCT to build on these events, creating long term structures and processes for involvement in all aspects of the commissioning cycle. Two way communications, a long term relationship and a full range of involvement activities will enable the trust and mutual understanding between the tPCT and communities to grow.

The Wheel will draw in as many BME organisations as possible as associate members and on its management committee. The relationship should be mutually advantageous.

As an independent body, The Wheel will be in a good position to promote partnerships between different community agencies. If the Wheel is attached to an existing BME organisation, it may be perceived as dominated and controlled by that organisation.

**16. Interim proposal**

**Maintain momentum**

Our project successfully involved over 20 people from BME communities. Some of these have moved on to employment, college or other activities but others may like to continue to create change in mental health services. In order to maintain their trust in the tPCT’s commitment to change, it is essential that there are continuing opportunities to get involved for those people who want to take them up as well as new people who have not been involved before. In order to do this, we suggest:

- Ensure adequate support
  Opportunities without the skilled and dedicated support required for potential participants are of no value. The DRE community development team at Sharing Voices...
and Roshni Ghar have a good track record in providing this kind of support and have played a major role in the successful participation of local people in the Outcomes and Commissioning Project. They and the Social Inclusion and Participation Worker (BDCT) currently provide the only known resource in Bradford able to fulfil the support role for mental health service users from BME communities who want to get involved in tPCT activities.

- **Begin by piloting and developing the work**

  This proposal therefore suggests that there is an allocation of funding within the tPCT (Public Health Community Development or Equality and Diversity team), to set up and oversee a part time worker, with community development skills, to work in partnership with and be supported by the DRE community development team for one year. During this time the strategy will be developed and implemented. Scope for bringing together the tPCT and DRE community development team may be explored through joint management or at a minimum, an advisory role. Work to be done during the development phase is likely to include:

  - **Implementation within the voluntary and community sector**

    Engaging the support of the voluntary and community sector, particularly those agencies and groups focused on BME communities and service user involvement. This requires developing trusting relationships over time.

  - **Connections with statutory sector providers**

    There would be considerable advantages if the involvement strategy had the support of all the statutory sector providers, including BDCT, the local authority and primary care services. These organisations may wish to contribute to the funding of the Involvement Wheel and to open up channels of communication with senior managers, if they feel this offers an opportunity to address shortcomings in their own feedback and planning processes.

  - **Integrating involvement within mental health commissioning**

    New structures, processes and skills will be required within the tPCT, particularly within the commissioning team, to enable channels of communication to open up and new ways of working to develop. This will take time to establish, but if they persist, it is likely that they will be one of the first PCTs to demonstrate progress in this area.

- **Integrating involvement within community development services**

  During an interim phase, the relationship and division of responsibilities between the BME Wheel of Involvement and existing community development activities will need to be considered. We suggest that the new structure builds on current activities, rather than just re-locating them. The DRE community development team should work closely with the Wheel to increase the level of participation overall, and not diminish their own activities of this kind. Supporting public participation is an important activity for DRE community development workers and plays an essential role within the overall remit of Sharing Voices and Roshni Ghar.

- **Developing an independent structure**

  To date, consultation with people from BME communities has emphasised that the BME Wheel should have its own independent constitution and management structure. This will need to be developed with continuing consultation to promote ownership.

- **Identifying resources**

  Estimated costs have been submitted to the tPCT. Over the year of development, it may be possible to agree resources from more than one source as suggested above.

  The tPCT could either include the costs of a limited amount of research activities in the overall budget, or these could be costed separately and reimbursed by those funding each research project.

- **Potential risks of under-resourcing the BME Wheel**

  If under-resourced the Wheel could exacerbate the disappointment and scepticism which followed previous initiatives (such as Participation, Why Bother? Blakey, 2005).
If under-resourced it could exacerbate rather than reduce community tensions by allowing one or two groups (and their voluntary sector organisations) to dominate.

**Next steps**

An implementation group has been set up by the tPCT, within the Equality and Diversity directorate, to take forward the strategy and commissioning framework.
References


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