

# **Mental Health Information Needs Of Black and Ethnic Communities In Central Manchester**

**A report on research into the views of service users  
and providers by Rohina T Ghafoor**

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# Chapter 1 – Introduction

## 1.1 Background

This study was commissioned by Central Manchester Primary Care Trust to Manchester Health Promotion Specialist Service with the support of Manchester Race and Health Forum

The Primary Care Trust's Health Improvement Programme shows mental health as a priority for the local population. The benefits of appropriate information for the effective prevention and management of mental health problems are recognised. It is clear that there is an increasing amount of information now available about mental health for those who can find it, yet for those who experience, or are at risk of, mental health problems, information is very hard to come by. This problem is more acute for people from black and minority ethnic communities.

The aim of the study was to inform the development of easily accessible information resources effectively targeted at people in a variety of different black and ethnic minority communities. It has therefore attempted to provide some practical guidance to those concerned with the production, management and distribution of information.

This study comprises,

- A review of initiatives and resources in other parts of the country/worldwide.
- The views of people from black and ethnic minority communities who use mental health services.
- The views of organisations representing or working with black and ethnic minority communities.
- The views of mental health service/information providers in different sectors.

The study does not draw comparisons between ethnic groups and also is not a critique of service provision. It intends to highlight issues amongst service users, carers and voluntary, independent and statutory sector services.

The study found that terminology remains problematic. Over the years not only has terminology changed but also meanings of words which can encompass a variety of political, social, racial and ethnic meanings. For example, referring to people as being South Asian is now preferred to saying they are from the Indian sub-continent.

This study does not define terminology except where people have defined their own ethnicity.

The study acknowledges and recognises the varied perceptions and understanding of mental health amongst the black and ethnic communities. The perceptions are further varied within each ethnic group, across generations and gender.

*“The concept of mental illness clearly differs from community to community and within some groups between generations”.* (Bingley et al. 2001)

Perceptions about mental health are further diversified due to culture, religious/spiritual belief systems and language.

## 1.2 The Position in Manchester

The study found that the previous deprivation indices (1991 1LC and 1998 1LD) and the new index of Multiple Deprivation 2000 consistently show the City of Manchester to be amongst the most deprived districts in the North West and in England. (The Manchester Planning Studies website).

It states that Manchester experiences extremes of severe deprivation and relative affluence within its boundaries. Ward level rankings clearly indicate severe deprivation exists in large areas of the City, including Benchill and Woodhouse Park in South Manchester and Harpurhey, Newton Heath, Central, Beswick and Clayton, Bradford, Ardwick, Moss Side and Gorton North in Central and North Manchester. All these wards fell into top 1% of the most deprived wards in England in 2000. Benchill has been ranked as the most deprived ward in the country. Harpurhey is the second most deprived ward in Manchester and in 16<sup>th</sup> place nationally.

Manchester is a culturally diverse city. Figures from the 1991 census shows that over 1 in 10 of the population come from an ethnic group (12.64%). Population projections suggest that this figure is likely to have increased to nearly 18% in 2001 and over 20% in 2006. One contributing factor has been the dispersal of asylum seekers to Manchester.

Many people in black and ethnic minority communities live in Manchester's most deprived wards.

Research on inequalities has shown consistently that people from ethnic minority groups are more likely to die younger and suffer more health problems than the majority of the white population. It is therefore important that health services are able to respond appropriately to health needs in culturally diverse communities.

The DETR indicates that the following Central Manchester wards are in the top 10% of wards sorted by rank according to the Index of Multiple Deprivation (August 2000).

- Levenshulme
- Ardwick
- Central
- Hulme
- Rusholme
- Gorton North
- Gorton South
- Whalley Range
- Moss Side

### 1.3 Race and Mental Health

Dissatisfaction voiced by users and service providers has led to an increase in funding for research into health care delivery for black and ethnic groups.

Short term funding to the voluntary sector enabled the provision of sensitive and acceptable services, but such moves are short term solutions to long term problems.

In the last two decades there has been a very little change in the way mental health services operate and cater to the needs of black and ethnic minority groups, although inclusion of cultural issues in the National Service Framework and the NHS Plan is testament to a growing awareness that existing practice is not culturally appropriate.

Research findings have shown an over representation of black groups, many of whom are from Muslim backgrounds, in the psychiatric system (Fernando 1995, Browne, 1997).

Furthermore, research has found that black and ethnic minority groups are more likely than the ethnic majority to be admitted to hospitals under compulsory sections of the Mental Health Act (1983), require urgent treatment and be placed on locked wards.

Black writers (Kareem & Littlewood, 1992; Fernando 1995; Robinson, 1995) have highlighted the mistreatment of black patients arguing that this stems from racial stereotyping and cultural imperialism adopted by mental health professionals, who view black and ethnic minority groups as being unable to express their emotions, hostile in attitude, not motivated for treatment and not psychologically minded.

Whilst conducting this study, some users stated that it was racism, lack of cultural understanding, or failure to understand their perception of their mental health or illness that has led to their needs not being met.

Professor Cochrane (1997) summarises these inter-related issues as follows: -

*“Psychiatry and the disciplines which support it, like psychology, are basically Eurocentric even when practised elsewhere in the world or by doctors from non-European cultural backgrounds.*

*Ethnic minority patients in Britain by definition come from cultural backgrounds, which differ from those of European origin . . . , there are maybe language barriers between psychiatrist and patient . . . , many psychological problems are described by analogies or in a local idiom (nervous breakdown, broken hearted, low spirit etc) which are culturally or linguistically specific . . . .*

*There are also well documented cultural differences in the way psychological problems may be perceived (eg somatic systems such as backache . . . )”.*

We cannot operate on the assumption of one common model and perception of mental health and illness.

Inappropriate models of mental health, racism and a failure to communicate at even a basic level with black and ethnic users, all undeniably exist.

Smaje (1995) has pointed out the lack of consensus in NHS policy documents addressing the needs of black people and ethnic minority groups. He identifies two main failings. Firstly, the failure to deal with the disparate problems faced by client groups. This means attempts to define their needs have been fragmentary at best. Secondly, failure to integrate local voices into practical policy with regards to issues such as religious and language needs and understanding of family structure. He states that measures taken so far in terms of ethnic monitoring, employment and consultation have not solved these at ground level.

*“The central problems of systematic disadvantage (judged, for example, on how low ethnic minority interests are on the list of management priorities) on the one hand, and unstable policy formulation (the fact that decisions are often ad hoc, short term and badly funded), on the other hand remains” (Smaje, 1995 p 2-3).*

This has been substantiated by the respondents’ experiences in this research study. One of the key issues raised by respondents was failure to get information due to a general lack of communication by professionals.

The National Service Framework for Mental Health re-affirms the issue of inappropriate services for black and ethnic minority communities.

Standard one requires services to work with both individuals and communities so that discrimination can be combated. The mental health services should work against social exclusion, especially with regards to people from black and minority groups. The standard states:

*“Combined evidence suggests that services are not adequately meeting mental health needs and that black and ethnic minorities lack confidence in mental health services. All mental health services must be planned and implemented in partnership with local communities, and involve service users and carers”.*

## **1.4 The Strategic Context**

Information for mental health is frequently dealt with in present day policy for health and social care. Policies speak of the need to improve information for people who use services and their carers.

### General context

The NHS Plan (2000) promotes a vision of health services focused on the patient needs and control, encouraging self care, preventive care and power and influence over the way the NHS works. The provision of information about our own health and the availability and choice of health services is an essential component of this change.

### Information Strategy

The Mental Health Information Strategy (Department of Health 2001) draws on the broader Information for Health (1998) strategy, the Information for Social Care

strategy and the Health Service's modernisation agenda. These information strategy documents all contain proposals about "consumer information", the key goals being: "To make information easily available to members of the general public on the nature, treatment and outlook of all types of mental illness." (the emphasis here is on the further development of NHS Direct) and the publication of local directories of services. It re-affirms the need for directories in a number of formats and languages to reflect the ethnic and cultural mix of local communities.

### National Service Frameworks

The National Service Frameworks (NSF) for mental health and for older people both make reference to the information needs of people with mental health problems and their carers. The NSF for mental health makes reference to the need for information for the public, service users and carers in relation to mental health promotion and the use of services in primary and secondary care. It makes particular reference to the need to inform people about access to self help and support services (e.g. housing or employment) as well as to mental health services and treatments.

Standard 6 identifies that "carers receive easy to understand information about both the help available to them and the services provided for the person for whom they are caring, including medication, other treatments, and care, and what to do and whom to contact in a crisis".

More broadly, the NSF comments on the need to develop and demonstrate "cultural competence" in mental health services. (Standards 3&4)

The NSF for older people refers to the need for information on treatment at key points in "care pathways", informed choice in packages of care and information for carers. It refers particularly to making services accessible to black and minority ethnic communities, stressing the need for "appropriate mechanisms" for communicating information. It also says that interpreting and translation services should be made available.

*"Information should be provided at a key point in care pathways, or stages of treatment. Many older people live with long term ill, frailty or disability; if they have appropriate information, they will be better able to participate in managing their own condition and their lives. Carers information needs should be met".* (Section 2.11)

*"Staff working with older people should also be provided with information so that they may be able to support older people by giving accurate and helpful information about additional sources of local help and advice".* (Section 2.17)

### Manchester Developments

In Manchester, the following developments will be significant in developing better information for mental health,

- Local Implementation Strategy for Information for Health, including a working group on information for the public
- Mental Health Information Strategy (Manchester Mental Health Joint Commissioning Executive)
- Mental Health Promotion Strategy and Social Inclusion Strategy.

- Patient Advice and Liaison Services (PALS), being established in each NHS trust.
- Review of interpreting services.
- Development of protocols for mental health services and treatment in primary care.

### The Law

From 2<sup>nd</sup> April 2001, the Race Relations Amendment Act (2000) requires all public authorities (and those bodies/persons whose function are of a public nature) not to discriminate on racial grounds in carrying out any of their functions. It also places new statutory requirements on public authorities to promote racial equality.

The need to provide a culturally competent information service can be seen in this context.

## Chapter 2 - Methodology

The purpose of this study was to provide an outline audit of the mental health information needs of black and ethnic communities.

The study was conducted in the Central Manchester Primary Care Trust area – Ardwick, Gorton North, Gorton South, Longsight, Rusholme, Moss Side, Hulme, Whalley Range, Chorlton and Levenshulme.

The study's proposal was to target the information needs of:

- those aged 16-18 years and above,
- people from the following communities – African, Bangladeshi, Caribbean, Chinese, Indian, Pakistani, and Vietnamese.
- refugees and asylum seekers
- carers

The restricted range means that the study was not able to research the needs of children and young people (under 16's), overseas and home students, and other communities: Irish, Polish, Greek, Jewish etc

The word “information” refers here primarily to:

- Information about mental health/illness conditions, treatments and self-help.
- Local information about mental health services and other sources of support and self-help.
- Information in a wide range of media.

A structured process and methodology, including semi-structured and in-depth interviews, were adopted.

This approach was used to enable an interactive dialogue with a wide range of service users, carers and organisations providing mental health services or working with black and ethnic minority communities. Interviews were conducted in English, Punjabi, Urdu and Hindi, and were recorded in writing.

The advantages of a semi-structured interview are that respondents can answer questions in as much detail as they want.

*“A qualitative semi-structured interview was used as it is flexible and powerful tool suited to new areas of researches of immediate clinical relevance (Britten, 1995).*

Semi-structured interviews allowed respondents to express their views freely and to elaborate on matters of importance to them within an overall framework that was set by the interview questions (see Appendix 1).

*“Qualitative interviews are interactive and hence more sensitive to subtle variations in language and concepts used by the interviewee following maximum in-depth information gathering taking full account of cultural and linguistic limitations (Britten, 1995)”.*

The study would like to acknowledge these issues that were discussed by respondents but are not dealt with in this report.

- domestic abuse/violence
- alcohol/drug abuse
- the greater number of black people amongst those subject to sectioning under the Mental Health Act, particularly by the Police.
- role of the Police with domestic abuse/violence, forced marriages and sectioning
- lack of services to prevent and support women in regards to female genital mutilation
- lack of mental health services for South Asian men
- lack of specific mental health services or care for refugee and asylum seekers
- the need to establish cultural, religious and spiritual care in mental health and other support services
- training for all providers

Many respondents were clear that there is a lack of opportunities and poor access to services due to racism and discrimination at all levels in public organisations.

Many respondents discussed their views and perceptions of mental health services and other support or specialist services.

During the semi-structured interviews, many respondents stated that the need for information cannot be divorced from the inappropriate provision of mental health services.

Finally, many users, carers and some providers had their doubts that this research study or other initiatives, like Agenda 2010 (Manchester City Council 2000), would bring effective change to promote racial equality.

## Chapter 3 – Service Users’ Responses

The term “users” is employed here to refer to people who use mental health services in the statutory, voluntary or independent sectors.

Semi-structured interviews were held with 80 users in total. This was facilitated through the voluntary and statutory staff working in black and ethnic minority communities.

Group interviews were arranged and permission sought from the users. Individual one-to-one interviews were also arranged and this was upon the request of the respondents who participated in this research study.

Although the focus of this research is qualitative, the number of people making particular responses to the questions was recorded. Below is a log of the number of specific replies to each question and qualitative information about the responses given. Some people were interviewed individually.

### 3.1 What are your experiences of seeking information on mental health?

Table 1

Received	Number
No Information	60
Some Information	15
Full Information	5
<b>Total</b>	<b>80</b>

Sixty respondents stated that they received no information, verbal, written or in any other format, regarding their diagnosis, medication and or any other treatment.

None of them were offered alternative care or therapies or any information for culturally appropriate self-help groups.

User’s quote:

*“I wanted information on schizophrenia for my carers and family but did not receive it, whilst I had been in hospital”.*

The next table highlights further details on the experience of the 60 respondents who had received no information.

Listed in Table 2 are services that participants referred to when they said they were given no information by them.

Table 2

Services	Number
General Practitioner	34
Hospital	11
Social Services	9
Voluntary Sector	6
<b>Total</b>	<b>60</b>

User's quote: -

*I was prescribed anti-depressants and my GP never explained to me either what the medication was nor the side effects”.*

Many respondents had similar experiences with their GP's. They stated that the GP does not spend time to explain information.

User's quote:

*“The GP recently informed me that I had early stages of dementia. My wife and I did not receive any information or an explanation”.*

The 9 respondents who received no information from Social Services stated that after referral has been made to the Department for assessment, there was no information on the outcome of the referral.

User's quote: -

*I did not hear from Social Services for many weeks. When the Social Worker finally arrived, he did not explain anything but he completed a long form”.*

**Table 3 highlights further details on the experience of the 15 respondents who received some information.**

These are services they were using at the time.

Table 3 Some Information

Services	Number
Voluntary Sector	7
Hospital	4
Social Services	3
General Practitioner	1
<b>Total</b>	<b>15</b>

User's quote:

*“I was given an information leaflet on schizophrenia and the medication, but the doctor did not explain what this meant to me or my family”*

**Table 4 highlights the details of the 5 respondents who received full information.**

List of services respondents are referring to.

Table 4 Full Information

Service	Number
Voluntary Sector	2
Social Services	1
General Practitioner	1
Hospital	1
<b>Total</b>	<b>5</b>

**The most commonly raised points were: -**

- Lack of information on diagnosis, medication and other treatments.
- Lack of information on alternative care to meet specific cultural and spiritual needs.
- Lack of information on self-help groups.
- Lack of information exchange between providers.
- Lack of understanding specific cultural and gender issues.
- Lack of multi-lingual information in a wide range of formats, e.g. leaflets, videos, audiotapes.

**3.2 Do you feel that the current information on mental health addresses the issues of race, culture, religious and spiritual life and your language?**

The majority of the respondents stated that all of these things are very important and one cannot be separated from the other. Also mentioned was the need for information to relate to issues of gender and disability.

Many respondents stated that they fear discussing their religious/spiritual beliefs as such beliefs are often dismissed or expressing them may lead to a misdiagnosis of mental health problems.

Some respondents felt their perceptions of what affects their mental well being, when expressed in the context of their belief system, has been seen as a symptom of a mental health problem and in some cases has led to sectioning.

User's quote:

*"It's racism. Psychiatry has always had institutional racism. Its whole process of assessing has been based on euro-centric principles and values to what it sees as normal and abnormal behaviour"*.

User's quote:

*"At hospital I informed them that it was my ancestral spirits affecting my life and the nurse failed to understand"*.

User's quote:

*"I attended counselling session only two times and then stopped. The counsellor didn't recognise or understand my family system"*.

**The following are the most commonly raised points by the respondents regarding the statutory service providers and white independent sector:**

- Minimal information available to meet their cultural needs.
- No information on spiritual care.

User's quote:

*"Whilst I was in hospital, I requested for a priest, as I believe it helps me to calm down but nothing was arranged (Christian)"*.

- No appropriate multi-lingual information in varied formats and in simple language.

User's quote:

*"I was given a leaflet in Urdu on schizophrenia but could not understand it".*

- Lack of information on where to access support from culturally appropriate services on issues such as domestic abuse, child abuse, drugs/alcohol misuse
- User's use of idiomatic expression has led to misunderstanding and or misdiagnosis by professionals.

User's quote (interpreted):

*"I told the nurse that I am not uloo. This meant that I am not stupid or mad but the nurse thought I was saying that I'm not an owl".*

It is important to recognise that we use language to communicate with each other to inform each other or gather information or understand one another, to express our needs, emotions, intentions and desires.

Hence, the language, words, expressions we use are not arbitrarily selected, they have specific meaning to that person. Appropriate use of language differs from one community to another, within each community and its sub-cultures, its meanings within formal or social settings and within between generations.

### **3.3 Have you experienced barriers to getting information on mental health?**

The most commonly raised points were: -

- GPs failed to provide information about diagnosis, treatments or alternatives. They should intervene at early stages to prevent crisis.
- Many respondents who have previously been sectioned stated that they were not informed of their right to appeal.
- Some of the respondents were told that they will have ECT but not informed what the treatment involved.
- Police do not always use an interpreter when sectioning.
- Inequalities in the justice system are barriers for people with mental health problems who become involved in it.
- The words 'mental health and illness' are barriers to people talking about mental health or getting information when they need it.

Many respondents stated that barriers to information are due to racial stereotyping, language barriers and discrimination.

### **3.4 What are your preferences for mental health education materials?**

All of the respondents (100%) stated 'face to face' information and 32 (40%) of these said "plus leaflet". Many people said that written materials should be bilingual, written in English in ways that address the cultural perspectives of the relevant communities, and then translated. The fact that there was complete agreement on "face to face" as a preferred means of getting information implies this is a preference across most communities and including people who are fluent in English.

A large majority (80%) would like culturally appropriate information for Primary Care and general practice staff to ensure that there is early intervention.

A fifth of respondents (20%) would like audio or videotapes and broadcasts through ethnic radio and television.

A few (10%) would like more user friendly and easily accessible information via the Internet.

The other key areas recommended by the respondents were: -

- Dramas in self-help groups, schools and colleges.
- Direct face to face information in places such as market places, community centres and spiritual places.
- Independent and confidential local multi-lingual telephone helpline.

### **3.5 Would you like to see improvements on information for mental health?**

(For example, in order to make appropriate referrals, enable effective networks of support in the community and to increase personal control and to live independently.)

Below are the respondents' views on changes needed to improve information on mental health: -

- To eliminate discrimination in the mental health service.
- More ethnic staff at all levels both in Primary and Secondary Care services.
- Effective communication at all levels within and across the sectors.
- To involve users directly in planning culturally appropriate services.
- To have more information on choices of alternative care rather than just conventional treatments.
- Mandatory training of all staff across the sectors on race and mental health.
- To develop spiritual care information and services.
- Trained interpreters should be provided across the health sector and in the Police.
- To involve the Police in addressing the issues of inequalities and their role in compulsory sectioning.
- To have trained ethnic minority staff in voluntary sector services that form part of a range of primary care provision to ensure effective and appropriate interventions.
- To improve standards of confidentiality in the voluntary sector and to increase community's confidence in staff skills

## Chapter 4 – Carers’ Responses

Twenty carers were interviewed and the Table 5 highlights the areas of care. The same methods were used to quantify some of the responses from the carers as were employed for service users.

Table 5 Areas of Care (diagnosis of the person cared for)

<b>Carers</b>	<b>Numbers</b>
Depression	7
Dementia	6
Schizophrenia	5
Others	2
<b>Total</b>	<b>20</b>

### 4.1 What are your experiences of seeking information on mental health?

Table 6 Depression

<b><u>Respondents</u></b>	<b><u>Number</u></b>
Full information	3
Some information	1
No information	3
<b>Total</b>	<b>7</b>

Three respondents received full information from their GP. The one who had got some information had received a leaflet in English, which he could not read.

The remaining three did not receive information from their GP. Of these, 2 received information from Longsight/Moss Side Project and 1 from African Caribbean Mental Health Project.

All the 7 respondents stated that no offer was made for alternative treatment. Of these, 4 stated that no information was provided on self-help groups.

One carer had contacted Social Services but did not receive appropriate information.

Table 7 Dementia

<b>Respondents</b>	<b>Numbers</b>
Full information	1
Some information	2
No information	3
<b>Total</b>	<b>6</b>

Of those receiving information, one respondent received it from hospital, one received some information from GP and the other from Social Services.

The remaining 3 did not receive information from the GP, Social Services or the hospital. From these, 2 received details from the Asian Carer’s Forum and were linked by the Forum with the Alzheimer’s Society. One stated that she did not know of any other place to receive information other than the GP.

All the 6 respondents stated that information was not available from their GP on culturally appropriate carer’s groups. Of these, one was aware of Manchester Carer’s Forum via the Social Services; the other 3 are involved in the Asian Carer’s Forum and the remaining 2 were not aware of support for carers.

Five respondents stated that it is a battle to get information from Social Services and it seems that carer’s needs are not considered important.

Carer’s quote:

*“Social Services does not live with my partner for 24 hours. I have more knowledge and awareness of my partner’s behaviour from day to day. My needs as a carer should be treated equally to those of my partner”.*

Table 8 Schizophrenia

<b>Respondents</b>	<b>Numbers</b>
Full information	3
Some information	1
No information	1
<b>Total</b>	<b>5</b>

Full information was provided to 3 respondents by their GP and 2 received information about the African Caribbean Mental Health Project and one was linked with Awaaz.

One respondent received some information by the GP but did not understand it. She received full information from the social worker via an interpreter.

One respondent received no information from the GP or any other agency.

Two respondents out of 20 interviewed did not know what diagnosis had been given for the people they are caring for, although they accompany them to Rawnsley Unit at Manchester Royal Infirmary.

**4.2 Do you feel that the current information on mental health addresses the issues of race, culture, religious and spiritual needs and your language?**

17 out of 20 respondents stated that all the statutory services failed to provide relevant information as regards the above.

The other 3 respondents were informed of ethnic minority voluntary sector provision but said that the GP themselves lacked cultural awareness or understanding of the family’s needs. Two of these 3 stated that the GP did not understand their spiritual perception on mental health.

All the 20 respondents stated that the services do not have the capacity appropriately to support the users or carers.

The 6 respondents who had linguistic needs stated that neither the GPs nor the other health services provide interpreters at all times. They questioned how the professional staff could have accurate information from users or give appropriate information to them.

Some said inequality in providing services is due to discrimination and lack of awareness and knowledge.

#### **4.3 Have you experienced barriers in getting information on mental health?**

20 carers said that they have experienced difficulty in getting information on mental health due to:

- racism in the mental health services. (The current euro-centric statutory and independent services are barriers to black and ethnic minority users even if there are black professionals in these agencies).
- stigma encountered by the family within their own community (there was discussion on the need to promote awareness about mental health in ethnic minority communities)
- not knowing where to begin looking to find information on mental health.

The 8 respondents who had received full information from their GP, as their first contact point, were not aware of where else to get information.

12 respondents commented on the lack of early intervention by their GP and only received a response at crisis stage.

Only 3 respondents aware of Manchester MIND but have no links.

The respondents stated that cases must be dealt with confidentiality, especially when sharing information with a third party.

The respondents stated that language is a barrier. This was expressed both by English speakers and respondents with linguistic needs.

#### **4.4 What are your preferences in mental health education materials?**

14 (70%) respondents would like face to face contact with leaflets in simple English and other languages.

A quarter (25%) of respondents would like face to face contact, followed up by a video in their first language.

All the carers (100%) would like all the information to be culturally and or spiritually appropriate.

#### **4.5 Where would you like to see improvements in information on mental health?**

(In order to increase personal control and to live independently, make appropriate referrals and enable effective networks of support in the community.)

These were the key areas where the 20 respondents would like to see improvement:

- local places for access to information.
- leaflets to be available at all public places.
- information pack for carers by statutory services with holistic approach.
- effective information exchange amongst services at both primary and secondary care about individual cases.
- compulsory training for all staff in public services on race and mental health, including black and ethnic minority staff.
- to improve confidentiality safeguards across services especially amongst the specialist services and the voluntary sector.

## Chapter 5 – Voluntary and Independent Sector Responses

At least 27 agencies or groups were interviewed. These were either specific black and ethnic minority services or had representation of black and ethnic minority users.

### 5.1 What are your experiences of seeking information on mental health?

Out of the 27 respondents, 20 had encountered difficulties in obtaining information. Their concerns were largely in relation to individual service users and the difficulties of being able to pass on good information, for example about diagnosis, treatment and medication.

There were also concerns about the flow of information about individual users between services, although this is beyond the scope of this research. Mentioned in particular were receiving good information upon referral of an individual to a voluntary sector service, being informed about the outcome of referral to a statutory service and access to information to enable an advocacy role when dealing with the Police.

The remaining 7 respondents had had varied experience with statutory services and voluntary sector services, and have knowledge and expertise on where to get information to meet both their own and user's needs.

### 5.2 Do you feel that current information on mental health addresses the issues of race, culture, religious and spiritual needs and your language?

Table 9 Current Information

Respondents	Number
No	20
Some	4
Yes	3
<b>Total</b>	<b>27</b>

The most commonly raised points by the 24 respondents were: -

There are no culturally appropriate translated leaflets. For example, two respondents have had to translate an English leaflet on schizophrenia for their users. One respondent had seen a leaflet in Urdu on schizophrenia but it was not culturally appropriate.

There is very little translated information at all for some languages on mental health and illness.

There are a couple of videos available but they do not contain local information.

No information is available to refer for spiritual care and treatment.

There is no central database for diverse information on mental health. For example, to find a support group for Pakistani people or an interpreter in a particular language.

There is a lack of accurate information for refugees and asylum seekers.

The respondents stated that information is a vital part of their work to enable them to provide an effective service.

Information derived from research would be useful. For example, why are refugee men from Sri Lanka often diagnosed with schizophrenia?

### 5.3 Have you experienced barriers in getting information on mental health?

Table 9 Barriers

Respondents	Number
Yes	20
Some	3
No	4
<b>Total</b>	<b>27</b>

- Out of the 20 respondents, 11 stated that language is a major barrier. This was also the case for English speakers.
- The statutory services lack awareness and knowledge of the best ways of working with diverse languages.
- 20 respondents stated that voluntary sector services should not be used as a 'dumping ground'. Eleven of them stressed that they are not an interpreting service. (These responses may imply a need for better information *about* voluntary sector services for users and for statutory services.)

*Respondent quote:*

*"There is a difference between a professional interpreter and a bilingual worker".*

- There is a lack of structured information and education on mental health targeted at the users, carers and voluntary sector staff.

23 respondents stated that the following were barriers to getting information.

- Racism and discrimination.
- Lack of communication amongst the service providers.
- Lack of joint working with voluntary sector.
- Lack of awareness of voluntary sector services.

Only 5 respondents out of 27 were aware of the recently published MIND Directory.

### 5.4 What are your preferences in mental health education materials?

The most commonly raised points were:

- To provide face to face, culturally appropriate information.

- ❑ Culturally appropriate translated leaflets. In particular, this means that written materials should acknowledge other concepts of what mental health is, reflecting views of particular communities, whether they are written in English or are translated.
- ❑ Holistic Central database to get information. For example: - Details of Black Counselling Service or herbal treatment for depression or where a local benefit advice service is or what ECT means.
- ❑ Information through other channels for public. For example: - Asian Sound Radio, Prime Television, Internet – specific website for black and ethnic minority people.
- ❑ Specific information for refugees and asylum seekers.
- ❑ Effective communication amongst the providers within each agency and with each other.
- ❑ Training for all staff in statutory and independent sector on race and mental health.
- ❑ Police should be trained on race and culture in the context of mental health.
- ❑ Need more accurate information about the relationship between ethnicity and sectioning (under the Mental Health Act) to address the problem of inequalities.
- ❑ A leaflet with details of all the local professional interpreting services.
- ❑ To involve users and carers in all the reviews, inspection and planning of mental health services to ensure they are culturally appropriate at all levels.
- ❑ Staff to reflect the local black and ethnic minority population in the statutory and white independent sectors.
- ❑ To eliminate the marginalisation of black and ethnic voluntary sector. Comments here involved the need for ethnic minority voluntary services to be equally valued and for them to be sufficiently resourced. Many felt they have no capacity to manage and disseminate information because of slender resources.
- ❑ To develop long term initiatives in the statutory service to bring real changes for future in working with diverse communities.

*Quote:*

*“Not the usual short-term fix projects in voluntary sector. Our role is to compliment the work of the statutory service and not to provide statutory responsibilities.”*

## Chapter 6 – Statutory Sector Responses

Group interviews were held with 13 teams who work with black and ethnic users. They were both generic (those not just for people with mental health problems) teams and specialist mental health teams, and this distinction is reflected in the responses they provided.

### 6.1 What are your experiences of seeking information on mental health?

Table 10 Experience of seeking information

Respondents	Number
Satisfied	6
Varied	2
Dissatisfied	5
<b>Total</b>	<b>13</b>

The 5 respondents who were dissatisfied were mostly concerned that not all the black and ethnic service users and/or their carers are properly informed due to cultural stereotyping and lack of understanding of family and belief systems.

They stated that the dismissal of the race and culture issues leads to misinformation and misunderstanding. For example, many black and ethnic users will describe their mental health problems either via somatic symptoms and/or in a spiritual context.

### 6.2 Do you feel that current information on mental health addresses the issues of race, culture, religious and spiritual needs and language needs of service users?

There were clear differences in the response to this question concerning the issue of religious/spiritual needs between specialist mental health teams and generic teams.

Eight out of 13 respondents stated that they do not have information on people's belief systems. They saw the religious/spiritual need as far too complicated to engage with and some stated that these beliefs contribute to individuals' mental health problems.

The remaining 5 respondents stated that belief systems are important to many users they come across and cannot be dismissed.

Some of the team members stated that they are informed on religious/spiritual needs but are not professionally trained to provide the information in the context of mental health and illness. They also acknowledged that they do not have diverse range of information for users and/or the carers that is culturally appropriate.

They stated that there is some multi lingual information but they do not have a range of leaflets on site for black and ethnic minority users and/or their carers.

Amongst the 8, a few team members had some knowledge of black and ethnic minority voluntary sector services.

The remaining 5 respondents stated that there is no information on black and ethnic voluntary sector services. They were aware of many reports and researches that have substantiated the fact of racism and discrimination in mental health service.

*Quote:*

*“It’s the ethnocentric knowledge base of western medicine versus race, culture and religious/spiritual values.”*

They emphasised that culture is transmitted through language. This causes misunderstanding and in some cases leads to misdiagnosis and or inappropriate sectioning.

### **6.3 Have you experienced barriers in information on mental health?**

Table 11 Barriers

<b>Respondents</b>	<b>Number</b>
Yes	7
Sometimes	3
None	3
<b>Total</b>	13

13 respondents highlighted a lack of training for staff on working with black and ethnic users and carers, especially on race and culture.

The 6 respondents who encountered barriers in getting information felt that this is due to the lack of a central database of information.

4 respondents stated that there is lack of updated information on black and ethnic minority voluntary sector mental health services.

2 respondents said they lacked information on which interpreting service to contact.

7 said the lack of training in information technology and poor access to the Internet is a barrier.

### **6.4 What are your preferences in mental health education materials?**

13 respondents agreed that there needs to be appropriately translated information on mental health.

13 respondents stated the need for a central database that has holistic information and can be contacted by telephone and the Internet.

7 respondents stated that face to face contact is the most effective way to give or receive information.

6 respondents said that face to face contact should be supplemented with culturally appropriate leaflets.

**6.5 Where would you like to see improvements in information for mental health?**  
(in order to increase personal control and to live independently, make appropriate referrals and enable effective networks of support in the community).

13 respondents would like a regular Race and Mental Health bulletin with national and local information in newsletters or the Internet.

8 respondents stated that mandatory staff training on race and mental health would encourage better information.

7 respondents would like training on working with professional interpreters.

9 respondents would like information on the Race Relations (Amendment) Act, (2000) and its implications.

6 respondents would like training on information technology in order to improve access to information on the Internet.

5 respondents would like to develop information on spiritual issues.

## Chapter 7 - Summary of What People Said

This is a summary of some of the main topics that have arisen from these discussions. They can be categorised as

- provision of, and access to, information
- mental health (and related) service provision
- how we understand mental health
- taboo
- spirituality

### 7.1 Provision of, and Access to, Information

Many users and carers stated that information is important to enable them to understand and manage their mental health/illness, to enable them to make an informed choice for treatment, to meet their cultural needs and to have personal control. Examples given included making a choice between anti-depressant and herbal medicine or counselling and spiritual therapy.

This was also affirmed by majority of the providers across the sectors.

There is general agreement that there is a lack of information about mental health, in any format, that is appropriate to the needs of black and ethnic minority communities. It is difficult to find what information there is.

There is general agreement that it is difficult to get information about local mental health services, or other supportive services.

Nearly everyone agreed that getting information directly from another person was the best way. Provision could be linked to relevant intervention points, for example, the Care Programme Approach planning or review

Many people thought that face to face information should be accompanied by an appropriate leaflet

There was a consensus amongst all the respondents for the need of a Manchester central information database. Improvement in information delivery as a result would not only benefit black and ethnic minority people, but all service users and carers. The database could work hand-in-hand with NHS Direct and other national specialist services and have accurate local information.

The database could contain a wide range of information, for example, details of trained black counsellors registered with British Association of Counselling, spiritual support from the Seventh Day Adventists or Reiki therapist registered with Complementary Medicine Association.

The database could be contacted by a phone line or the Internet by any member of the public. Local services could use it to provide information.

The database would be accessible to users, carers, local voluntary/independent and statutory services.

There is a need to ensure that information, advice and help is available for 24 hours a day, 365 days a year. A number of phonenumber services already provide this.

None of these respondents mentioned public library as a place to obtain information.

## 7.2 Mental Health (and related) Service Provision

A theme running through many of the responses in this research was the inevitable difficulty of separating matters to do with information from more general issues about service provision.

Most of the points raised about service provision are negative but positive suggestions for change were made. It is worth listing some of the points most often raised since they do show what people feel lies behind the lack of appropriate information, i.e. the lack of information for people using services is a symptom of more general organisational problems. These can be summarised as

- Stereotyping, racism and discrimination.
- Inappropriate, unacceptable and irrelevant services, i.e. ones that people don't want to use
- Lack of appropriate information about what is involved in using a service, e.g. questions of confidentiality, your rights and options,
- Lack of appreciation for religious and cultural differences.
- Problems in managing language and communication difficulties.

Many respondents to this research thought that training for people working in all relevant organisations was an important remedy to these problems. Of these, many felt that such training should be compulsory in the light of past difficulties in attracting staff to training on topics of this nature.

### Cultural Competence

A culturally competent service is the one that is able to provide an appropriate high quality, professional service to all those who wish, or need to, use that service. A person's racial, ethnic, cultural or religious background should not be a barrier their being able to make full and proper use of that service.

Information provision and design should be informed by anti-discriminatory values which include guarding against deliberate or unwitting prejudice, ignorance, thoughtlessness or racist stereotyping against black and ethnic minority people.

The Stephen Lawrence Inquiry Report concluded that: -

*"It is incumbent upon every institution to examine their policies and the outcome of their policies and practices to guard against disadvantaging any section of the community".*

Mental Health Service providers and other support services are no exception to this principle and should develop a structured approach in this area.

## 7.3 Taboo

A common issue raised by users and carers were the taboo/stigma of having mental health problems/illness. There was a fear that a person with mental health problems will be isolated from the community to which he/she belongs.

There may be no shared language with which to describe feelings and distress. The very closeness of the community may prevent dialogue with those wanting to help. The result is that many who suffer mental health problems will only come into contact with mental health services when all else has failed and there is a crisis which cannot be managed.

Many young users, especially young women, felt that they have been misunderstood. They said that they had experienced inter-generational conflict, but have deep respect for their parents. They are often indirect contrast of the communities and cultures they belong to. Some of them had experienced difficulties in obtaining information. Firstly, they do not know where to start, then the providers are culturally incompetent and the young users experience racial stereotyping.

This strong stigmatisation of discussion about mental health and mental illness will need too inform how information on mental health is produced and distributed.

#### **7.4 Understanding Mental Health**

It is clear from discussions that took place during this research that a fundamental problem for those who wish to ensure better information is how to talk about mental health. Respondents commonly referred to a medical view of mental health that is predominantly from the “Western world”.

This view is not shared by many people from different cultures, and is not understood by some people, so conceptual ideas like “depression” and other diagnostic categories are often not used or are a source of misunderstanding.

Respondents in this research pointed to the need for greater appreciation of alternative ways of expressing mental distress and to the importance of reflecting these perspectives in sources of information.

#### **7.5 Religion and Spirituality**

Many respondents said that their understanding of their mental health is closely bound to their religious and spiritual beliefs. Furthermore, spiritual beliefs and participation in religious organisations and activity are seen as an important source of strength and support in dealing with poor mental health. These comments represent a complex range of needs, from those who require support for simple activities like praying, to those who are seeking more demanding interventions, like exorcism.

A number of discussions dwelt on the need to incorporate this perspective into information about mental health, and to consider the need to provide information about religious organisations and spiritual healing when promoting sources of support. The availability, quality and cost of spiritual healing services was raised since some people end up paying substantially for such services and others question their quality and competence. Information about spiritual healing would, ideally, contain reference to quality, competence and cost, implying a need to take advice from suitably learned authorities in this area.

## Chapter 8 – Recommendations

### 1. Information Strategy

- The information strategies of the Manchester Mental Health Joint Commissioning Executive and the Manchester Mental Health Care Trust should include measures to improve the provision of information for mental health to black and ethnic minority communities.

### 2. Publicity about service providers

- Mental health (and related) services should publicise what they provide in written formats, ideally including information on the following,
  - commitment to equal access to the service
  - appropriate guarantees of confidentiality
  - translation of key information in addition to English
  - rights and choices in relation to support and treatment.
- Organisation should incorporate its commitment to race equality into its public relations and media strategies and promote successful work in this area through the media.

### 3. Service organisation

- Organisations providing a service for people with mental health problems and /or their carers require information management systems that enable provision of information to people from a wide range of cultural and linguistic backgrounds. This will include access to information about other supporting organisations and available information about mental health problems, treatments and alternatives.
- Organisations providing a service for people with mental health problems and /or their carers should systematically make information available, in order to increase choice and control for the service user, at key points of contact, e.g. at referral assessment, diagnosis and referral for treatment, at Care Programme planning and review.
- Organisations providing a service for people with mental health problems and /or their carers should incorporate standards on provision of appropriate information into relevant policy and audit, e.g. equality policy.

### 4. Training

Relevant training for staff working in mental health (and related) services is recognised in this research as a necessary precondition to the provision of more and better information. Organisations should

- Formally adopt a policy on staff training for the provision of mental health care to a multi-racial and culturally diverse population and which is consistent with the organisation's wider staff development and training strategy.
- Adopt staff induction procedures which include providing information/awareness of the organisation's equal opportunities and related policies.

- Provide all staff with mandatory basic training, specific to their job function, to equip them to provide a culturally competent service to all users and carers.
- Ensure that race equality and diversity issues are fully integrated into management development training programmes.
- Ensure that training programmes are competency based and that learning is assessed, where appropriate, in work settings.

## **5. Interpreting Services**

- Organisations providing for people with mental health problems and their carers should take responsibility for ensuring their staff's access to high quality interpretation services.
- All staff who have contact with users and carers should be made aware of current arrangements for meeting the users' and carers' interpreting needs.
- All staff who may work with interpreters should receive training of how to work in 3-way communication.
- Interpreters used/employed should have been trained in: -
  - providing a high quality interpretation.
  - maintaining confidentiality

N.B. A review of interpreting services in Manchester has been undertaken and is expected to report in due course.

## **6. Manchester Central Database**

The need for a large amount of diverse information to be well managed, quickly available to busy people and kept up to date led many respondents in this research to consider a centralised database as an efficient solution. This would be one of the ways, within the overall system, to provide culturally appropriate information. Such a database would need to be easily contactable by phone or computer. It would require

- exploration of how to develop a database, including identifying a managing organisation and sustainable funding.
- Involvement of users and carers in its development.

## **7. Religion and Spirituality**

This was identified in the research as a general area of concern. Significant action would include

- Organisations should develop policies, in collaboration with their users, on how to meet their religious and spiritual needs.
- The general provision of information should include details of how to contact appropriate religious organisations as complementary sources of support. Organisations can make this provision more effective by making working links with religious organisations for the benefit of their users.

- There is a need to find out more about demand for the services of spiritual healers for mental health problems and how services in the voluntary and statutory sector can respond to such demand.
- Written information resources should reflect the range of beliefs current in Manchester's population and not dismiss or ignore them.

### **8. Developing a greater range of appropriate and useful information resources.**

There is a general lack of information resources about mental health for black and minority ethnic communities that needs to be addressed in association with people from those communities. This could result in both the acquisition and distribution of nationally available materials and the creation of new materials that are more locally relevant.

### **9. How to produce and provide information**

- written information is felt to be useful as an addition to face to face information provision. Written information should
  - reflect other ways of understanding mental health prevalent in the target population. Where people have different beliefs about the origin of problems or a different way of expressing their experiences, these should be acknowledged and respected alongside more Western/medical perspectives.
  - terminology specific to the language of psychiatry or psychology should be explained in terms of relevant experience, e.g. hearing voices, not sleeping well, and so on.

*N.B. These approaches will also be important when providing information verbally.*

- judgements about whether to translate material have to be made according to many different circumstances. This research indicates that translated information targeting a particular ethnic minority community should be written alongside an English text to cater for the diverse language skills within each community and within families or caring support systems.
- Other forms of media for information are important, e.g. audiotapes, videos, posters.
- There is a value in using commercial black and ethnic minority media e.g. television and radio channels and newspapers as an effective way of informing general populations within different ethnic minority groups.

## **Project to Research Mental Health Information Needs of Ethnic Minority Groups in Central Manchester**

### **Format**

- Background
- Confidentiality
- Process of the Qualitative Research Study

### **Questions**

1. What are your experiences of seeking **information on mental health**?

*Where do you go for information on services, diagnosis, treatment/medication, self help groups, choices of care/treatment, alternative care, etc?*

2. Do you feel that current **information on mental health** addresses the issues of:

- \*Race
- \*Cultural
- \*Religious/spiritual
- \*Linguistic needs?

3. Have you experienced barriers in accessing **information on mental health**?

*What were these barriers?*

4. What are your preferences in mental health education materials?

*How would you like the format of the information?*

Where would you like to see the improvements on **information about mental health** in order to:

- \*increase personal control and to live independently
- \*make appropriate referrals
- \*enable effective networks of support in the community

5. I have asked you everything that I wanted today; is there anything else that you would like to add or comment on?

*Appendix 2. Participating organisations, groups and individuals.*

**Acknowledgements to all the respondents who gave their time to participate in this research study.**

**Voluntary and Independent Sector**

1. Afro Caribbean Care Group
2. Indian Senior Citizen's Centre
3. Gita Bhevan
4. Pakistani Resource Centre
5. Pakistani Community Association
6. Wai Yin Chinese Women's Society
7. Chinese Health and Information Centre
8. Longsight and Moss Side Community Project
9. Broad African Representative Council
10. African Women's Centre
11. African and Caribbean Mental Health Service
12. Manchester Bangladeshi Women's Organisation
13. Black Health Agency
14. Ageing Well Project, Age Concern, Manchester
15. Bibini Family Support Services
16. Elderly Asian Development Group
17. Alpha Counselling Service
18. Refugee Action
19. Alzheimer's Society, Manchester Branch
20. 42<sup>nd</sup> Street
21. Citizen Advice Bureau, City Centre Office
22. Creative Support
23. Manchester University Counselling Service
24. Haween Support Network
25. Refugee Support Network
26. Black Health Forum
27. Nepalese Association
28. Sri Lanka (UK) Friendship Association
29. J.N.R. 8

**Statutory Sector**

Dr Lovell, Senior Research Fellow, Manchester University

South Asian Mental Health Services, Manchester Mental Health Partnership

Manchester Health Linkworker Service

Linkworker Service, Manchester Social Services

Young Asian Women's Project

Linkworker Service, (Citywide )

Manchester Mental Health Partnership – Older People’s Services

Manchester Mental Health Partnership - Adult Services

Manchester Mental Health Partnership, Community Mental Health Teams Longsight and Moss Side

Manchester Advice, Mental Health Team

Linkworker’s Services, Central Manchester and Manchester Children’s University Hospital NHS Trust

M4 Translation, Manchester City Council

**Individual**

Barrington Reeves (Freelance Trainer)

**Organisations that provided advice and information.**

Consultancy Services to the Voluntary and Statutory Services, Vauxhall, London.

Ethnic Alcohol Consultancy Services, Hounslow, London.

Department of Spiritual, Religious and Cultural Care, East Ham Memorial Hospital, London.

Confederation of Indian Organisations (UK), London.

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