



COMMUNITY ENGAGEMENT PROJECT:
(The NIMHE Mental Health Programme)

REPORT OF THE COMMUNITY LED RESEARCH PROJECT FOCUSING ON
MENTAL HEALTH SERVICE NEEDS OF SOUTH ASIAN COMMUNITIES,
IN LONDON BOROUGH OF WALTHAM FOREST

BY THE QALB MENTAL HEALTH CENTRE

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with

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Funded by the NIMHE managed and supported by
The Centre for Ethnicity and Health, University of Central Lancashire.



RESEARCHERS PROFILES

The following people were involved in the development and delivery of this Project:

(1) Yasser Ahmed:

I am 26 years old and lives in Walthamstow with my wife and a daughter. I am currently employed by the Qalb Centre as a Case Worker. I have qualifications in Mental Health as well as being a qualified TEFL teacher. I gained pre-GCSE schooling in Pakistan where I learnt to speak Urdu fluently and gained a deeper understanding of the Pakistani culture and its complexities. I was awarded Uclan Certificate in Community Research and Drugs, in 2004, when I was involved in a similar project researching drug use among the Pakistani community in Waltham Forest.

(2) Mohammad Afzal:

My name is Afzal Mohammad. I have been a member of Qalb for about 5 years. The training course has been very interesting and it has helped me understand about Mental Health issues as I was in a NHS Rehab for 2 years. I have also studied film and filmmaking in the past.

(3) Qadir Bakhsh:

I am a graduate with substantial experience of community work in and around Waltham Forest. I joined the project as a coordinator in April, 2006, but have been involved with the Director of the Qalb Centre since November, 2005, in preparing research proposal and recruiting the research team. I have research experience and social and public policy development in different service provision areas.

(4) Yasmin Choudhry:

My name is Yasmin Choudhry. I manage all the Qalb Projects. I am a qualified therapist. I had been involved in the previous community engagement programme and very pleased to be part of this programme too. My main role is to provide overall support for the success of the project and attend external meetings to inform others and collect information for the team.

(5) Naheed Malik:

My name is Nahid Malik and I am currently a service user of Mental Health involved in the research project. Despite my mental health problems I have managed to achieve great academic heights by obtaining a Masters Degree in Education (Guidance & Counselling Skills), a BSc joint honours degree in Psychology and Education and a Diploma in Counselling.

My motto is “Don’t let any hurdle stop you from achieving what you want to”
I have previously had extensive experience of working in the field of mental health and in the care profession generally. I am currently involved in the DRE project as a researcher making an invaluable contribution

(6) Haseeb Mehmood:

I am a graduate and currently working on part time basis at the Qalb Day Care Centre as admin support and case worker. I am engaged to set of systems to collect stats and provide information for monitoring reports. I am IT skills and have worked on the Drug Project in the past helping to analyze data and prepared tables and pie charts. At the Day care centre I update the files of the clients and have acquired thorough knowledge of mental health issues and concerns.

(7) Seema Gupta

My name is Seema gupta. I am a current service user at the Qalb Mental Health Day Centre and involved in the research project. Prior to my mental challenges becoming severe, I was a full-time teacher, specialising in secondary school Mathematics and Early Year Education. I have worked in state and private educational institutions from 3-18 years and the community adult education service in roles of Nursery teacher, Mathematics tutor and teaching English to speakers of other languages.

I am a graduate with PHCE in Mathematics, CELTA and a Certificate in Early Childhood Education.

(8) Yusuf Parkar

My name is Yusuf Parkar. I live in Waltham Forest. I have been a member of the Qalb Day Care Centre for the past three and half years. Going to Qalb has helped me get better. I hope I can contribute to the research. Having suffered from mental health in the past makes me more aware of mental health issues.

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We are grateful to the members of the DRE steering committee for their contributions, Najat Elwakeli in particular. We would like to mention Harjit Bansal, the Diversity Manager and Clinical Lead at Goodmays Hospital for her guidance and support and for arranging ethical approval from NELMHT.

Action research is a process towards achieving a desired social policy goal. This research report has listed a number of conclusions and recommendations. We sincerely hope that commensurate progress is made by those in position to make a difference. Based on the views expressed by the majority of our informants, the report draws attention to specific measures to create inclusive and culturally competent service provision, incorporating not only the linguistic, cultural and religious needs of clients, but by considering deep rooted centuries old value and belief systems and specific factors contributing to their mental ill health, in order to make services more accessible to mental health services users in Waltham Forest, particularly of South Asian origin.

Above all we sincerely hope that community engagement would be sustained and extended with the contacts we have been able to make through this project.

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EXECUTIVE SUMMARY

Aim

The aim of the community engagement – action research project was to explore the availability of mental health services for South Asian communities in Waltham Forest, and ascertain views of both the service users and the professionals on their appropriateness with regard to faiths, cultures, and diversity generally, and suggest how they could be improved.

Context

Since 2000 over 200-community groups have taken part in one or other of the University of Central Lancashire's Centre for Ethnicity and Health's Community Engagement Programmes, financially supported by the Department of Health The Qalb Mental Health Centre was one of 40 community groups who took part in the National Institute for Mental Health in England's Community Engagement Programme between 2005 and 2007. The objectives of the programme were to deliver improved equality of access, experience, and outcomes for Black and minority ethnic mental health service users..

The Qalb Mental Health Centre established in 1993 aims to provide a therapeutic and practical support for Asian people with short term and long term mental health problems.

Delivering Race Equality in Mental Health Care

Delivering Race Equality (*DRE*) is identified as a priority in successfully delivering modernised, mainstreamed and inclusive mental health services. The National Service Framework (1999) proposes that people with mental health problems can expect services that are both non-discriminatory and well suited to those who use them.

The delivery of *DRE* is measured and implemented against both national (*DRE*, DoH, 2005) and local plans (*Delivering DRE in NELMHT services Action Plan, 2005 – 2008*)¹. *DRE* sets out a race equality action plan with the aim of systematically addressing the needs of BME communities and in providing more equitable mental health care for BME groups. Thus through the national implementation of *DRE*, mental health services are envisioned to be characterised by features fundamental to addressing the needs of BME groups.

The following are relevant to the delivery of race equality in primary care mental health services:

- Less fear of mental health services among BME communities and service users;
- Increased satisfaction with services;

¹ Delivering race equality in mental health care and The Government's response to the independent inquiry of the death into David Bennett, DoH (2005).

- An increase in the proportion of BME service users who feel they have recovered from their illness;
- A more balanced range of effective therapies...interventions that are culturally appropriate and effective;
- A more active role for BME communities and BME service users in the training of professionals, development, planning and provision of services
- A work force capable of delivering appropriate and responsive mental health services to BME communities.

Both the local and national action plan for delivering race equality in Waltham Forest mental health services (2005 – 2008) is based on the 3 building blocks proposed within *DRE* (DoH, 2005):

- (1) More appropriate and responsive services**
- (2) Community engagement –**
- (3) Better information -**

Key drivers

In addition to the above mentioned anti-discrimination and human rights legislations and the following specific national drivers are very important in the context of DRE.

- *Delivering Race Equality [October 2003]*
- *Inside / Outside [March 2003]*
- *Breaking the Circles of Fear*
- *David Bennett Inquiry*

Focus of the Research (Community Engagement) Project

Besides the core information related to the sample, the research focused around further three key areas.

(1) CORE INFORMATION

Age, gender, disability, ethnicity, sexuality, religion, socioeconomic status, (specified by the University)

(2) PERSONAL EXPERIENCES

- Service-users' perception of mental illness and signs and symptoms
- Exploring extent and patterns of their illnesses
- Quality of experiences in accessing services,
- Perception of barriers to accessing quality services

(3) PERCEPTION OF CULTURALLY COMPETENT SERVICES and EXPERIENCES

- Services users' views about culturally competent services
- Whether they have received any cultural competent service

(4) 2010 VISION – SOME ASPECTS

- Service users specific fears as barriers
- Satisfaction level
- Perception of violence, seclusion, and therapies

It was envisaged to empower and facilitate mental health service users and their carers (as workers/ researchers and volunteers) in engaging with mental health service providers to voice their needs for shaping the mental health services provided for them. To this end a number of mental health services users and key workers were engaged as researchers, who participated in various platforms to air their views and were successful in engaging with the wider ‘user community’.

Sample and Ethics

There was no set numbers for informal interviews or discussions, however prior to designing the questionnaire at least 4 focused discussions were held among the research team, who were predominantly service users and key workers... Around 50 questionnaires were completed by users, over the age of 16 and 25 professionals completed another specific questionnaire. It is estimated that in total over 250 people contributed to the research process in one way or the other, including members of the steering committee, cluster group and participants at seminars, and conferences, and one to one discussions.

Discussion

In discussing the findings and other aspects, the following themes emerged:

(1) DRE awareness:

2010 visions would only become reality if all the stakeholders, including face workers are fully engaged in delivering the programme and achieving targets.

(2) Research Findings

The cliché comments about the cultural competent services provision were all too common i.e. provision of halal food, prayer corner, Asian staff and interpretation. However there was candid admission by some professionals that:

“Cultural and Mental Health difficulties are synonymous. Mental Health professionals find it difficult to work with both and rely hereby upon a Western psychiatric model, of course”.

It was generally believed that with regard to the values and beliefs system of Asian communities, professional can hardly scratch the surface. It is difficult to reach the centuries old deep-rooted value systems and their current experiences, too. As one of the professional respondent observed:

“Understanding racist practises by Mental Health staff, lack of choice in treatment to BME, Eurocentric treatment procedures, and failing therapies seen not appropriate for BME”.

The challenge is to get to ‘under the skin’ information and hope that the information is not used against the community, by way of stereotyping them further.

Both the professionals who completed questionnaires and those services users who contributed to the focus group debates felt strongly that the deep-rooted value and belief systems were very important. Therefore it is imperative to understand the backgrounds of the Asian communities for appropriate diagnosis and treatment.

Whereas there are still those professionals who believe that *“The mental health system should not be specific to any certain culture but to have a normal standard of **values of this country**”*, - a very assimilationist view: and a colour blind view expressed by another professional.

There was a view that prescribing drugs seems less costly compared to longer term intervention, *“particularly when you are sure not sure what to do any way”*, said one of the professionals.

(3) Fear of Stigmatisation

Reluctance to share personal information with professionals)

(4) Personal and Team Development

Numerous opportunities for the researchers, predominantly mental health services for personal and team development

(5) Appointment of Asian Staff

Need for more Asian staff, however any staff trained in Eurocentric traditions, including Asians, African Caribbeans or any other BME origin, would not necessarily have the skills or the knowledge for ‘Trancultural orientated’ mental health work, unless they are re-trained.

(6) Perception gap: ‘singing from the same hymn sheet’

There seems to be general consensus for **‘doing different things; and doing things differently’**, among the professionals, users, carers and volunteers, in terms of policy and practice and expectations, but there is disparity and gap, between ‘need analysis/ needs recognition’ and ‘meeting those needs’.

(7) Mainstreaming and targeted work

There is no doubt that ‘mainstreaming’ services for ethnic minorities and other excluded and marginalised communities is the ultimate goal of most services providers.

The philosophy and the policy to develop and provide a comprehensive and fully integrated range of services for all the residents must nevertheless recognise the need for special and separate services provision for all those who are at risk for being excluded

Conclusions

The following sources of evidence were used to draw conclusions and make recommendations:

Seminar/launch report, focus groups, one to one, conferences and seminars, literature review (inc. findings of 11 pilot projects), questionnaires, deliberations at DRE steering committee and Cluster Group meetings, Community Engaging Network meetings – weekly team meetings and fortnightly meetings with support workers.

The conclusions were drawn around the following areas:

- **Personal experiences**
- **DRE Awareness**
- **Differential and discriminatory conduct**
- **Appreciation for cultural sensitivity**
- **Satisfaction with cultural responsiveness**
- **Significance of faith and spirituality**
- **Differential patterns of mental illnesses**
- **Perception of Carers roles and need for support**
- **Over medication**
- **Involvement of families and communities**
- **Views about 12 characteristics**

Recommendations

Similarly the recommendations focused on the following areas addressing both communities and the professionals:

- **Dissemination of research findings**
- **Socio-cultural and religious implications for cultural-competency**
- **Faith sensitive services**
- **Support for targeted Service Provision**
- **Medication and alternative therapies and wide ranging treatment**
- **It is recommended that instead of heavy reliance on medication, wide ranging alternative therapies should be offered e.g. talking therapies etc.**
- **DRE Agenda and Action plan**
- **Hook on to what is already in existence**
- **Appropriate staffing**
- **Training & (training the users' trainers)**
- **Confidence & trust**
- **Suggestions for improvement**
- **Accessibility and advocacy**
- **Public education among the Asian communities**
- **Partnerships Working**
- **Combating specific fears**
- **Mainstreaming VS targeted work**
- **Role of Ethnic/Faith Media**

1. INTRODUCTION

1.1. The Background to National Community Engagement Project

The Centre for Ethnicity and Health's Model of community engagement

We often hear the following words or phrases:

- Community consultation
- Community representation
- Community involvement/participation
- Community empowerment
- Community development
- Community engagement

Sometimes these terms are used inter-changeably; sometimes one term is used by different people to mean different things. The Centre for Ethnicity and Health has a very specific notion of community engagement. The Centre's model of community engagement evolved over several years as a result of its involvement in a number of projects. Perhaps the most important milestone however came in November 2000, when the Department of Health (DH) awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire (Uclan) to administer and support a new grants initiative. The initiative aimed to get local Black and minority ethnic community groups across England to conduct their own needs assessments, in relation to drugs education, prevention, and treatment services.

The DH had two key things in mind when it commissioned the work; first, the DH wanted a number of reports to be produced that would highlight the drug-related needs of a range of Black and minority ethnic communities. Second, and to an extent even more important, was the process by which this was to be done.

If all the DH had wanted was a needs assessment and a 'glossy report', they could have commissioned researchers and produced yet another set of reports that may have had little long term impact. However this scheme was to be different. The DH was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about drugs, or anything about undertaking a needs assessment at the start of the project; however they would have proven access to the communities they were working with, the potential to be supported and trained, and the infrastructure to conduct such a piece of work. They would be able to use the nine-month process to learn about drug related issues, and how to undertake a needs assessment. They would be able to benefit and learn from the training and support

that the Ethnicity and Health Unit would provide, and they would learn from actually managing and undertaking the work. In this way, at the end of the process, there would be a number of individuals left behind in the community who would have gained from undertaking this work. They would have learned about drugs, and learned about the needs of their communities, and they would be able to continue to articulate those needs to their local service providers, and their local Drug Action Teams (DATs). It was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

The model has since been developed and refined, and has been applied to a number of areas of work. These include:

- Substance misuse
- Criminal justice system
- Policing
- Sexual health
- Mental health
- Regeneration
- Higher education
- Asylum seekers and refugees

New communities have also been brought into the programme: although Black and minority ethnic communities remain a focus to the work, the Centre has also worked with:

- Young people
- People with disabilities
- Service user groups
- Victims of domestic violence
- Gay, lesbian and bi-sexual and trans-gender people
- Women
- White deprived communities
- Rural communities

In addition to the DH, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, and the National Institute for Mental Health in England, the Greater London Authority, New Scotland Yard and Aimhigher.

1.2. The key ingredients of the model

According to the Centre for Ethnicity and Health model, a community engagement project must have the community at its very heart. In order to achieve this, it is essential to work through a host community organisation. This may be an existing community group, but it might also be necessary to set up a group for this specific purpose of conducting the community engagement research.

The key thing is that this host community organisation should have good links to the defined target community², such that it is able to recruit a number of people from the target community to take part in the project and to do the work (see section on task below).

It is important that the host community organisation is able to co-ordinate the work, and provides an infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day-to-day activities of the project. One of the first tasks that this host community organisation undertakes is to recruit a number of people from the target community to work on the project.

The second key ingredient is the research task that the community undertakes. According to the Centre for Ethnicity and Health model, this must be something that is meaningful, time limited and manageable. Nearly all of the community engagement projects have involved communities in undertaking a piece of research or a consultation exercise within their own communities. In some cases there has been an initial resistance to doing ‘yet another piece of research’, but this misses the point. As in the initial programme run on behalf of the DH, the process and its outcomes have equal importance. The task or activity is something around which lots of other things will happen over the lifetime of the project. Individuals will learn and new partnerships will be formed. Besides, it is important not to lose sight of the fact that it will be the first time that these individuals have undertaken a research project.

The final ingredient, according to the Centre for Ethnicity and Health’s model, is the provision of appropriate support and guidance. It is not expected that community groups offer their time and input for free. Typically a payment in the region of £15-20,000 will be made available to the host organisation. It is expected that the bulk of this money will be used to pay people from the target community as community researchers³. A named member of staff from the community engagement team is allocated as a project support worker. This person will visit the project for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers throughout the project. The University also provides a package of training, typically in the form of a series of accredited workshops.

² The target community may be defined in a number of ways – in many of the community engagement projects it has been defined by ethnicity. We have also worked with projects where it has been defined by some other criteria, such as age (e.g. young people); gender (e.g. women); sexuality (e.g. gay men); service users (e.g. users of drug services or mental health service users); geography (e.g. within a particular ward or estate) or by some other label that people can identify with (e.g. victims of domestic violence, sex workers).

³ This is not always possible, for example, where potential participants are in receipt of state benefits and where to receive payment would leave the participant worse off.

The accredited workshops give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to form an appropriate steering group to support the project⁴.

The steering group is an essential element of the project: it helps the community researchers to identify the community they are engaging with, and can also facilitate the long term sustainability of the projects recommendations and outcomes. The community researchers undertake a needs assessment or a consultation exercise. However the steering group will ensure that the work that the group undertakes sits with local priorities and strategies; also that there is a mechanism for picking up the findings and recommendations identified by the research. The steering group can also support individuals' career development as they progress through the project

1.3. The community engagement team

The community engagement team comprises of senior support workers, support workers, teaching and learning staff, administration team and a communications officer. They work across a range of community engagement areas of specialisation, within a tight regional framework.

Table 1: National Programme Directors

National Programme Directors			
Northern Team	Midlands Team	Southern Team	Senior Programme Advisors
Senior Support Worker		Senior Support Worker	
Support Workers	Support Workers	Support Workers	Drug Interventions Programme
			Citizen Shaped Policing
Teaching And Learning Team			
Administration Team			
Communications Officer			

1.4. Programme outcomes

Each group involved in the Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community. The qualitative themes that emerge from the reports are often very powerful. Such information is key to commissioning and planning services for diverse and 'hard to reach' communities. Often

⁴ Very often we will have helped groups to do this very early on in the process at the point at which they are applying to take part in the project.

new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

In 2005/-6 the Substance Misuse Community Engagement Programme was externally evaluated. This concluded that:

- the Community Engagement Programme had made very significant contributions to increasing awareness of substance misuse and understanding of the substance misuse needs of the participating communities. It also raised awareness of the corresponding specialist services available and of the wider policy and strategy context.
- the Community Engagement Programme had enabled many new networks and professional relationships to be formed and that DATs appreciated the links they had made as a result of the programme (and the improvements in existing contacts) and stated their intentions to maintain those links.
- most commissioners reported that they had gained useful information, awareness and evidence about the nature and substance misuse service needs of the participating organisations.
- all DATs reported positive change in their relationship with the community organisations. They stated that the Community Engagement Programme reports would inform their plans for the development of appropriate services in the future.
- A significant number of the links established between DATs and community organisations as part of the Community Engagement Programme were made for the first time.
- The majority of community organisations reported their influence over commissioners had improved.
- Training and access to education was successful and widely appreciated. 379 people went through an accredited University education programme.
- A third of community organisations in the first tranche reported that new services had been developed as a result of the Community Engagement Programme.
- The vast majority of participants and stakeholders expressed high levels of satisfaction with the project.

The capacity building of the individuals and groups involved in the programme is often one of the key outcomes. Over 20% of those who are formally trained go on to find work in a related field.

The views expressed in the report are those of the group that undertook the work, and are not necessarily those of the Centre for Ethnicity and Health at the University of Central Lancashire.

1.5. General Demographics and South Asian Communities

National Profile

In the 2001 Census, out of the total UK population of 58.8 million there were 4.6 million from the ethnic minorities or 7.9% of the total. Just over half of the all the ethnic

minorities were of South East Asian origin or ‘Asians’ or ‘Black Asians’ and a quarter of African Caribbean origin, e.g. ‘Black’ or ‘Black British’.

Table 2: Britain’s Multi-Ethnic Population

Category	Population	Population (%)	Ethnic minority (%)
White	54153898	92.1%	n/a
Mixed	677117	1.2%	14.6%
Asian/Asian British			
Indian	1053411	1.8%	22.7%
Pakistani	747285	1.3%	16.1 %
Bangladeshi	283063	0.5%	6.1%
Other Asians	247664	0.4%	5.3%
Black/Black British			
Black Caribbean	565876	1.0%	12.2%
Black African	485277	0.8%	10.5%
Black Other	97585	0.2%	2.1%
Chinese	247403	0.4%	5.3%
Other	230615	0.4%	5.3%
Total ethnic minorities	4635296	7.9%	100%
Total Population	58789194	100%	n/a

Source: Census, 2001

The 2001 Census collected information not only about ethnicity but also about religious identity. Among other faiths, the largest groups are Pakistani Muslims (658,000) and Indian Hindus (467,000). The Indian ethnic group is religiously diverse, including Hindus, Sikhs, and Muslims. In contrast, the Pakistani and Bangladeshi groups are more homogeneous, Muslims accounting for 92 per cent of each ethnic group (Census, 2001).

London Borough of Waltham Forest – A profile

According to the 2001 Census (OPCS, 2002), the Borough had 218,341 people, of whom 35.5% were from Black and Ethnic Minority (BME) groups. By mid 2003 the estimated population was 221,600. The proportion of local population of BME groups had increased by 10% since 1991 (from 25.6% to 35.5%). The proportion of BME population in the Borough was higher than national average in England and Wales (8.7%) and for London overall (28.8%).

The total Asian population in the borough is 14.8%. Black people, mainly from African and Caribbean backgrounds, made up 15.4% of the population, with the Chinese and others total a further 1.8%. Thus, the BME total represents over a third of the population. The three largest BME groups in Waltham Forest were black Caribbeans (8.2%), Pakistani (7.9%), and black African (5.8%). This Borough has the second largest population of Pakistani community in all the London Boroughs.

The age profile of the BME population in the Borough was younger than the white population. Over half (51.6%) of all the children under five were from BME groups. Some 56.8% of respondents in the Borough gave their religion as Christian, similar to the London average of 58.2%. The next largest religion affiliation was Muslim, which accounted for 15.1% of the population. At 32,902 people, this was the third largest Muslim population in London. (Census, 2001). 25% of the population of the Borough was born outside the UK. The proportions are lower among those aged 0-15 and those of pension age, and higher among those of working age.

A large number of languages are spoken in the Borough. The ten most frequently requested languages from the Council's interpretation and translation service are Turkish, Albanian, Somali, Urdu, French, Polish, Portuguese, Arabic, Romanian and Spanish.

The inhabitants in most of the wards, which are located in the south of the Borough, experience a high level of deprivation, poverty, unemployment and poor housing, experienced by all the residents, but proportionately more by Black and ethnic minority communities.

The unemployment rate in the Borough was 4.9 per cent of all economically active people aged 16-74, compared with those of Black African origin, who had the highest level of unemployment at 17%, followed by 'Other Black' at 15%, Pakistani at 14%, and those of mixed origin at 13%.

1.6. The focus of this report

Since 2000 over 200-community groups have taken part in the Centre for Ethnicity and Health's various Community Engagement Programmes.

The Qalb Mental Health Centre was one of 40 community groups who took part in the National Institute for Mental Health in England's Community Engagement Programme between 2005 and 2007. The objectives of the programme were to deliver improved equality of access, experience, and outcomes for Black and minority ethnic mental health service users by:

- building capacity in the non-statutory sector
- encouraging the engagement of Black and minority ethnic communities in the commissioning process
- ensuring a better understanding by the statutory sector of the innovative approaches that are used in the non-statutory sector
- involving Black and minority ethnic communities in identifying needs and in the design and delivery of more appropriate, effective and responsive services
- ensuring greater community participation in, and ownership of, mental health services
- allowing local populations to influence the way services are planned and delivered
- contributing to workforce development, and specifically the recruitment of 500 Community Development Workers.

The Qalb Mental Health Centre

Established in 1993 the Qalb Centre aims to provide a therapeutic and practical support for Asian people with short term and long term mental health problems.

The Centre provides Counselling Services 4 days a week, including 36 hours of counselling for alcohol and drug users, commissioned by the Waltham Forest DAAT.

The Centre offers a range of services to adults and their carers under a Service Level Agreement with the local social services department.

They receive referrals from the local mental health team and other agencies e.g. GPs and also accept self referrals from clients already in the system.

The project is divided across two centres providing different services.

THE QALB DAY SERVICE is based in the lower ground floor of Waltham Forest Business Centre on Blackhorse Lane, and provides a service to 15 users at any given time.

The second service is *THE QALB COUNSELLING SERVICE*, which is based at the Ferguson Centre, in Lower Hall Lane, Walthamstow.

Besides these two main services provided in Waltham Forest, the centre also runs a respite care service – *DISCOVERY HOUSE*, in Tower Hamlet's.

Delivering Race Equality in Mental Health Care

Besides the activities mentioned above, the Qalb Centre also participates in a variety of local and national programmes. For example in 2004 they were awarded a community engagement project, funded by the Department of Health and managed by the University of Central Lancashire to carry out drug use needs assessment among the local Pakistani community. Currently they are running a befriending programme for mental health services users.

Early in the 2006 they were successful in their bid to establish this community engagement programme, aimed at *Delivering Race Equality in Mental Health Care*, specifically for South Asian Community in the Borough.

Delivering Race Equality (*DRE*) is identified as a priority in successfully delivering modernised, mainstreamed and inclusive mental health services. The National Service Framework (1999) proposes that people with mental health problems can expect services that are both non-discriminatory and well suited to those who use them. Breaking the Circles of Fear review (2002, SCMH) details numerous issues related to the problems and circle of fear relationship between BME communities and mental health services, documenting limited primary care provision for BME communities, undervalued BME community initiatives and the social exclusion of minority groups.

The Inside Outside report, DoH (2003) identifies the need to address three key objectives:

- To reduce and eliminate ethnic inequalities in mental health service experience and outcome;
- To develop the cultural capability of mental health services;
- To engage the community and build capacity through community development workers.

The Count Me In National Mental Health and Ethnicity Census (Health Care Commission, NELMHT, 2005) identified local needs for action in delivering race equality that are also reflected on a national level.

The delivery of *DRE* is measured and implemented against both national (DRE, DoH, 2005) and local plans (Delivering DRE in NELMHT services Action Plan, 2005 – 2008)⁵. The national standards for delivering DRE is routed in existing legislation, Race Relations (Amendment) Act (2000), Human Rights Act (1998). The RR (A) act (2000) states that specified public authorities have a general duty to work towards the elimination of unlawful discrimination and to promote equality of opportunity and good relations between persons of different racial groups. Further, it states that services have a duty to assess and monitor functions in accordance with race equality.

The essential shared care capabilities (SCMH, 2004)⁶ sets out a set of shared standards in promoting shared workforce practice in respecting diversity and promoting non-judgemental and anti-discriminatory practice, challenging inequality and engaging with communities to identify needs, barriers and opportunities for improvement.

DRE sets out a race equality action plan with the aim of systematically addressing the needs of BME communities and in providing more equitable mental health care for BME groups. Thus through the national implementation of *DRE*, mental health services are envisioned to be characterised by features fundamental to addressing the needs of BME groups.

The following are relevant to the delivery of race equality in primary care mental health services:

- Less fear of mental health services among BME communities and service users;
- Increased satisfaction with services;
- An increase in the proportion of BME service users who feel they have recovered from their illness;
- A more balanced range of effective therapies...interventions that are culturally appropriate and effective;
- A more active role for BME communities and BME service users in the training of professionals, development, planning and provision of services
- A work force capable of delivering appropriate and responsive mental health services to BME communities.

⁵ Delivering race equality in mental health care and The Government's response to the independent inquiry of the death into David Bennett, DoH (2005).

⁶ The Sainsbury's centre for Mental Health

The race equality scheme (RES) for Waltham Forest PCT (2005) sets out a clear objective of working with voluntary and community organisations to review mental health support needs for black people and ensure that reconfiguration of mental health services take full account of the needs of BME groups.

The local action plan for delivering race equality in Waltham Forest mental health services (2005 – 2008) is based on the 3 building blocks proposed within *DRE* (DoH, 2005):

DRE's programme of change is founded on these three building blocks;

(1) More appropriate and responsive services - achieved through action to develop organisations and the workforce, to improve clinical services and to improve services for specific groups, such as older people, asylum seekers, and refugees, ***BME groups***, and children. ***Work force development***: BME community input into service planning and input for the induction and training for new primary care staff

(2) Community engagement - delivered through healthier communities and by action to engage communities in planning services and accessing services, supported by 500 new Community Development Workers. ***CDW key functions include change agent, service developer, capacity -builder, and access facilitator to services.***

(3) Better information - from improved monitoring of ethnicity, better dissemination of information and good practice, and by improving knowledge about effective services. This includes a new yearly census of ethnicity of mental health patients. **(Please note that *Italic bold* = WFPCT Emphasis)**

1.7. Review of background materials relevant to the project

A number of key reports and policy drivers have been mentioned in 1.6. above. In this section a brief analysis of findings of pilot projects, is presented as part of literature review.

Mental Health and Community Engagement – Analysis of Findings of 11 pilot projects

Introduction

Before embarking on the community engagement programme in mental health, during 2006/07, the University of Central Lancashire supported a number of pilot projects. Hereunder, analyses and summary of findings of 11 such pilot projects are presented. All the groups had similar focus i.e. what are the mental health needs of certain specific BME groups as defined by themselves, why were they not accessing services provided in their locality, whether the services were responsive to their needs, exploring relationship between ethnicity, religion, personal identity and emotional well being and impact of 'immigration' 'asylum' related issues, status and their experiences.

These 11 groups were located in London, Manchester, Liverpool, Luton, Derby, Bradford, Bedfordshire, and Kent.

Over 900 participants both male and female informed the research process, representing a cross section of BME communities and Refugees & Asylum Seekers. They were South Asians, African Caribbeans, Irish and Arabic speaking communities. They were predominantly Muslims, but included Christian, Hindus and Sikh as well.

Approximately 50 community researchers representing a cross section of the communities mentioned above carried out the work. A significant number of these researchers were mental health service users both male and female.

A variety of research methods, i.e. one to one interviews, focus group meetings, semi structured interviews and questionnaires were used by the researchers.

Themes

The thematic analysis of the findings of the projects is presented hereunder. It is important to note that a number of themes include composite responses from a number of projects, whereas certain specific responses only relate to a single project e.g. “Over 60% had experience of mental health problems (themselves, family, or friends). Nearly 1/5 had been hospitalised”. This particular quotation relates to responses of one group. In one case the group in question has been identified.

1. Needs assessment

- Specific needs of South Asian women who have escaped domestic violence and/or forced marriages (e.g. around dependency and confidence).
- Understanding of South Asian culture and family issues by the people they tend to seek the help from.
- Strong identity of the sample as Muslim and implications for responsive services.
- Shame and stigma was an issue for some within the community, and need for help to overcome feelings of shame and isolation.

2. Type of illness (Symptom, Signs and Experiences)

- Depressions, ‘emotional pain’, anxiety, sleep problems, and mood swings were common feelings experienced by victims of DV.
- A significant number had experienced domestic violence – most for more than 5 years. Although husbands were usually the perpetrators of DV, other family members could also be perpetrators (e.g. mother-in-law)
- Over 60% had experience of mental health problems (themselves, family or friends). Nearly 1/5 had been hospitalised. (Findings of one group).
- In terms of awareness – respondents seemed most aware of mental health problems related to depression and schizophrenia.

- Depression, stress, fear and loneliness were common amongst the sample (reported one of the group) – only half had ever sought any help with any of these feelings however, mainly because people didn't know that help might be available or where to go.
- Mood swings, anxiety, memory loss, sleep problems, flashbacks, nightmares were common amongst another sample.
- Most of the sample, of a refugee group, had experienced problems associated with separation from family and friends, violence, war, persecution or finance related issues.
- Bereavement, displacement, torture, persecution, and destruction of home were a common experience, cited by another refugee group.

3. Fears, Anxieties, and Barriers

- Fear of mental health services (e.g. compulsory admission)
- Victims of domestic violence often feel shame. Stigma and honour may prevent people from seeking help
- GP's are often the first point of call for people who do seek help, who often get anti-depressants prescribed.
- Feelings of not being accepted, labelled, and stereo-typed by the wider community.
- Public responses to events such as 9/11 and 7/7 impact on the sense of well-being within the community.

4. Barriers and Obstacles

- A third of the sample was afraid of trying to access services as they thought that this might impact negatively on their applications for asylum. (reported one group).
- Section 55 of the Nationality Immigration and Asylum and Act 2002 was seen as preventing access not only to financial and housing support but also to healthcare.
- Two thirds of the sample could not communicate in English – many of those who had some grasp of English struggled to understand what was being said to them by English speaking officials/service providers.(A Refugee group reported)
- Most relied on friends or contacts in the community to interpret for them. Only a small proportion had had access to a professional interpreter. (a refugee group reported)
- The community tended to perceive mental health problems in a very narrow way (i.e. associated with serious mental illness and hospital admission)
- Women who have uncertain immigration status can face particular problems – their status can be used as a means of control by perpetrators and it can also be a barrier to seeking help (fear of deportation).
- Immigrant women may also face problems with language.
- Feelings of shame, stigma, and isolation and fear of re-percussion were greatest barriers to seeking help. Financial dependency was also an issue.

5. Reasons and dynamics

5.1. Common experiences of the sample prior to arrival in the UK included:

The following findings relate to an African refugees, Asylum seekers and new migrants group in Luton.

- Financial problems (38%).
- Separation from family (25%).
- War (21%).
- Violence (21%).
- Torture (16%).
- Bereavement (14%).
- Persecution (13%).

5.2. Common experiences of the sample following arrival in the UK included:

The following findings (% responses) also relate to the same group from Luton, mentioned above.

- Unemployment (42%).
- Financial problems (35%).
- Separation from family (32%).
- Language (27%).
- Racial abuse (21%).
- Uncertainty about status (16%).
- Family problems (16%).
- Social isolation (14%).
- Homelessness (13%).
- Poor housing and lack of access to education, employment, and training is likely to impact negatively on mental health.
- Over a third of the sample reported forced marriages.
- Over two thirds reported domestic violence.
- Lack of independence was also reported as an issue by a third of the sample.
- There was a considerable delay between being the victim of domestic violence and seeking help
- Lack of contact and separation from family contributed to feelings of sadness and depression for around one third of the sample.
- Broader issues such as housing and community safety have a significant impact on mental well-being. This is particularly so within the context of racism and community cohesion or poor community relations.

6. Coping Mechanisms

6.1 Faith and Family

- People saw the church as having a significant role in the delivery of support for people with mental health problems,
- Although the links between the church and mental health services were unclear, respondents thought that churches could provide referral, community education and pastoral care for people with mental health problems.

- People saw faith as teaching them tolerance and empathy for those who were ill and helping to keep them grounded and centred at times of stress. Prayer helped to ‘unburden them’ for example.
- Having someone to listen and someone to talk to was seen as an important adjunct to prescribed medication.
- Most people handled mental health problems on their own, or with the support of family and friends. Some sort help from an Imam.
- Having someone to listen to and someone to talk to was seen as an important adjunct to prescribed medication.
- Use of alcohol and other drugs as a means of improving mood, but often had negative consequences.
- More work needed in relation to (a) alcohol and (b) specific groups of Irish people such as travellers, second generation, and mental health service users.
- There was generally good awareness amongst respondents of the links between alcohol and mental.

7. Mainstream Treatments

- Concerns were expressed about inadequate care and racism within the mental health system
- Medication (either on its own or in combination with counselling or hospital admission) was the most common treatment.

8. Actions suggested

8.1. Accessibility and Advocacy

- Greater and easier access to a wide range of health and social care services (including employment, housing etc.).
- Greater availability and access to interpreters.
- There is a need for an advocacy role to support refugees and asylum seekers.
- Difficulty with independent living and daily lives (e.g. housing, paying bills).
- Relied on support from family.
- GP’s were likely to be the first point of contact for most people seeking help.

8.2. Information – health promotion

- More and better information about mental health and mental health services – including in community languages.
- More community awareness raising – in part to help reduce stigma.
- Better education and involvement of families
- Clear and simple information about the help that is available and how to access it is needed in community languages.
- Community events and publicity to increase awareness and reduce stigma and embarrassment.

8.3. Partnerships Working

- Partnership with religious organisations.

- Building stronger links and partnerships between faith organisations and mental health services to deliver better community education, reduce stigma, facilitate referral, and assist with prevention and recovery.
- More involvement of families in treatment.
- Greater partnerships between South Asian communities (including service user and carer groups) and mental health services/commissioning groups. This will involve funding and capacity building.

8.4. Support and Capacity Building

- Support for families and friends.
- Spiritual support.
- Peer support.
- Low threshold preventative mental health services should be delivered via BME community organisations that are easily accessed by the community.
- Greater integration of social care and support to enhance capacity to live independently.
- More aftercare support following discharge.
- Key role of family in providing support – but many families were themselves unsupported in trying to provide this (e.g. in terms of knowledge around mental health).
- There was a considerable desire for personal development amongst the samples (e.g. through education)

8.5. Social inclusion initiatives

- Better housing and employment.
- Generally better living conditions.

8.6. Training and development of staff

- Training for staff providing mental health and other services around South Asian communities.
- Training and toolkits to assist GPs to identify and work with DV Development of peer support.
- Training and awareness raising for mental health professionals, as well as for communities.

8.7. Responsive service delivery

- Mainstream services to be more ‘culturally appropriate’ – inc. provision of appropriate food.
- Better in-patient provision (food, activities, language).
- That ethnic monitoring information is better used to inform the development of services for Irish communities.
- “Services that demonstrated an understanding of Irish history and culture”.
- Training for people in a range of generic and specialist services around the specific needs of working with South Asian women and domestic violence and forced marriage – looking out for it, knowing what to do, awareness of issues such as family and honour.

- Integration of Alims//Muftis/Sheikhs/Hakims into mental health services to offer an alternative perspective and alternative treatments.
- Provision of gender specific services.
- Adequate provision of prayer and ablution facilities in residential services.
- Training on Islamic understandings and interpretation of mental health for statutory and voluntary sector staff.
- For the NHS to move away from the dominant medical model of mental health and for people to have more choice (e.g. services delivered within an Islamic framework that offers Islamic interpretations of mental distress and Islamic paths to recovery. Alims and Muftis should be supported to work alongside the NHS so that supplications and advice that can aid recovery can be integrated into treatment.
- Provision of appropriate facilities – halal food, prayer facilities, direction of prayer, safe spaces for women, gender specific services.

8.8. Appropriate Staffing

- More BME staff.
- All staff to be professional and well trained staff – to be treated with dignity and respect – to have an active role in treatment (e.g. to have treatment explained properly), – choice (including choice of worker and the right to be treated at home).
- Development of workforce programmes (including volunteering schemes) for South Asian communities.

8.9. Intervention strategies

- More preventative services/initiatives.
- Talking interventions.

8.10. Design, and Delivery of Services)

- To be more involved in treatment – choice.
- Counselling, befriending and drop-in services with greater involvement of other service users.

8.11. Range of treatments

- Greater range of treatment was advocated.
- After care seemed to be limited – families were often the main source of support.
- Broader range of treatments needs to be developed including appropriate day-time activities and talking therapies.
- Often given limited information about diagnosis, or about options for or aims of treatment.
- There was a general criticism that treatment appeared to be limited to ‘pills’ whereas people felt that having someone to talk to and listen to them was most important.
- Availability of broader range of services (i.e. social inclusion – beyond medication).

- A greater range of help – someone to talk to who would understand – counsellors from minority ethnic backgrounds.
- Self help and discussion groups.
- Religious and spiritual explanations and treatment for mental health problems were central to some of the participants’ understanding of mental health and to recovery. This was rarely available from generic services however.
- People who had used ‘talking therapies’ (e.g. psychologist, social worker, counsellor, user group) seemed generally happy with them.
- People didn’t seem to be aware of treatment plans.

1.8. The Qalb Centre Community Engagement Project

Aim of the Community Engagement Project

The aim of the project was to explore what mental health services were available for the Black and minority ethnic communities in Waltham Forest, and comment on their appropriateness with regard to faiths, cultures and diversity generally, and suggest how they could be improved, addressing diversity implications.

Objectives

- (a) To highlight the service experiences of BME mental health service users and their carers’.
- (b) In the light of (a) above, to make recommendations that will contribute to the delivery of better mental health services for BME communities in line with *Delivering Race Equality in Mental Health Care*.
- (c) To recommend action plans specifically for *Delivering Race Equality*, designed to deliver on three key aims (i) equality of access, (ii) equality of experience and (iii) equality of outcomes
- (d) To work closely with key stakeholders in Focused Implementation Sites towards making Delivering Race Equality happen on the ground, by various means.
- (e) To articulate new and innovative ideas and assess efforts and strategies developed by various Mental health service providers about how to go about delivering some of the outcome envisaged in DRE. (See Section (VI) below)
- (f) To empower and facilitate mental health service users and their carers (as workers /researchers and volunteers) in engaging with mental health service providers to voice their needs in shaping the mental health services, which are appropriate to their needs?

It is pertinent to mention here that the above cited research objectives have direct relationship with the learning objectives of all the key stakeholders, i.e. users themselves and their carers, the mental health institutions and professionals with regard to sensitive policy formulation, resources allocation and sensitive services planning and delivery.

Research Focus

Besides the core information related to the sample, the research focused around three key areas, elaborated as 2, 3 and 4 below, but expanded in Section 3.2.

(1) CORE INFORMATION

Age, gender, disability, ethnicity, sexuality, religion, socioeconomic status, (specified by the University)

(2) PERSONAL EXPERIENCES

- Service users' perception of mental illness and signs and symptoms
- Exploring extent and patterns of their illnesses
- Quality of experiences in accessing services,
- Perception of barriers to accessing quality services

(3) PERCEPTION OF CULTURALLY COMPETENT SERVICES and EXPERIENCES

- Service users' views about culturally competent services
- Whether they have received any cultural competent service

(4) 2010 VISION – SOME ASPECTS

- Service users' specific fears as barriers
- Satisfaction level
- Perception of violence, seclusion, and therapies

Link between the local DRE action plan and CEP

The local Action Plan for DRE is very comprehensive addressing all the three building blocks referred to above, including the 12 characteristics of 2010 vision and requirements of the Race Relations (Amendment) Act, 2000, besides other drivers.

The 'Community Engagement' Building Block is strongly linked to the Community Engagement Programme (CEP) with a view to capturing experiences of South Asian communities in the Mental Health Services Provision vis-à-vis cultural competency and perception of and experiences of exclusion etc. (Please see the Research Focus above). The CEP no doubt relates to the two other building blocks to see effectiveness of efforts and document outcome measures, if possible.

Any information gathered during the process is meant to feed into the accomplishment of two other building blocks and the development of the work programme of the Community Development Worker(s).

The CEP is able to identify a number of key community stakeholders, including users and carers or key workers within the voluntary sector in order to contribute to the achievement of DRE goals.

As part of the programme a detailed report is produced with conclusions and recommendations for ensuing work of the DRE steering committee and particularly sustaining community engagement.

Throughout the research/engagement process guidance and support was sought from the local DRE Steering Committee and the focus was adjusted, if needed, to contribute to their action plan for DRE, e.g. our research design & research tools were approved by them and the sample recommended by them was used.

2. RESEARCH METHODS

2.1. The Research Team and their Role

Eight researchers: 5 male and 3 female, were recruited. Five of the eight were service users and two are key-workers, representing a cross section of the Asian communities, i.e. languages, cultures and religions. One of the eight was research coordinator.

A circular letter was sent to key local organisations and it was advertised to the Qalb Centre Day Care users. 14 individuals showed interest, who were sent all the relevant information about the projects. 12 of the 14 were individually interviewed by the research coordinator and the Director of the Qalb Centre and eventually 7 of them were appointed to carry out the research.

Distinct steps were taken for team development and to skill the researchers, enabling them to accomplish desired goals. Throughout the duration of the project fortnightly meetings were held with the support worker, provided by the university. He met with the team individually as well for individual personal development and guiding them individually for their 'assignments work' in pursuit of University qualification. Initially the coordinator met with the team on a weekly basis to articulate research focus and develop research tool. These weekly meetings were used as sort of focus group meetings 'with the users and key mental health workers' to capture issues and concerns.

Five of the seven workers attended all the 7 full training days provided by the University of Central Lancashire. Two members of the team had already attended the research methods days, therefore they only attended the two days on 'mental health' training.

The research team and the project per se were supported by the DRE Steering Committee, comprising officials of the local PCT and the Mental Health Trust, besides other voluntary sector groups.

The seven Community researchers were accountable to the Research Co-ordinator and the Director of the Qalb Centre. Both of them oversaw the project on a day to day basis. The Co-ordinator, besides meeting the team both individually and as a team once a week, also contacted them by e-mail, and provided and disseminated information received from various sources i.e. Uclan or PCT.

Besides personal and team development, referred to above, the team members, both individually and collectively performed various tasks e.g.

- Organised half day seminar to launch the research project (attended by 50 delegates). Besides various speakers, three members of the team spoke as well, at the seminar. A 40-page seminar report was also produced to inform the research process and

contribute to the deliberation of the Steering Committee. (See Section 4.4.3. for further details)

- Three Members of the research team attended briefing session and the conference and two of them spoke, at an international conference on ‘Changing role of Mental Health Professionals’ organised by the University of Central Lancashire.
- All the team members collectively prepared and piloted the questionnaire, collected and analysed the data and contributed to the final report.
- The coordinator, the Director of the Centre and the University Support worker attended the DRE Steering Committee meetings and the North East London Cluster Group, both to seek help and support and to contribute to their action plan. The coordinator and team members attended the Research Projects Network meetings, organised by the London Development Centre.
- The Director of the Centre and the Coordinator jointly contributed a chapter in Dr. Suman Fernando’s forthcoming book *Mental Health in a Multi-ethnic Society: Promoting Racial Equality and Justice*. (second edition) - explaining the role of the Qalb Centre generally ‘for making it happen’ and its roles as being instrumental in local research, referring to DRE as well.
- As has been reported earlier the Qalb Centre is based in London Borough of Waltham Forest, therefore the researchers and the participants came from various districts in Waltham Forest i.e. Leyton, Leytonstone, Chingford and Walthamstow and the data was collected at various institutions in the Borough, accessing various groups, centres and institutions – in-patients, rehabilitation, day care and developmental groups e.g.
 - Naseberry –
 - Stonlea
 - Woodbury
 - The Qalb Day Care Centre,
 - The Ferguson Centre
 - Thornbury
 - CREST
 - Black Peoples’ Mental Health Project
 - Women’s and Men’s groups at Ferguson centre

2.2. Various Research Methods

Various research techniques and methods were deployed to gather information e.g.

(a) Review of literature and gathering secondary research findings. Review of relevant literature was carried out related to 12 characteristics of 2010 vision. A great deal of information was collected by the sub committee of the Local Implementation Team and

North East London Cluster group, as part of their action plans. The research coordinator and the Director of the Qalb Centre had access to all their papers, as members of these groups, therefore any information gathering was built upon, what was already available to avoid duplication e.g. value added project

- (b) Desktop research (a number of documents and reports were accessed through the Internet)
- (c) One to one, round table and focus groups meetings were held, involving;
 - a. Mental Health Service users
 - b. Professionals e.g. GPs, mental health key workers, CPNs, Counsellors, and therapists
 - c. Parents and carers,
 - d. Services providers – policy and face work levels
- (d) Open-ended and semi-structured interviews were held, and
- (e) Two comprehensive questionnaires were prepared and administered to users over the age of 16 and various professionals e.g. Nurses, GPs, Key Mental Health workers, both within the statutory and voluntary sectors.
- (f) The DRE Steering Committee (i.e. Waltham Forest sub committee of the Local Implementation Team) steered the research project, comprising various professionals representing PCT, NELMHT and local voluntary sector, who positive contributed, debated, and advised.
- (g) Besides attending the DRE steering committee meetings, the members of the research team attended the North East London Cluster Group meetings as well, comprising representatives of four PCTs in the NELMHT area.
- (h) The members of the research team attended one national and one international conference as participants and speakers and also participated in the Community Engagement Networking Group meetings, which informed the research process and consequently the outcomes.
- (i) A half day seminar was held involving 9 different speakers, giving different perspectives and attended by 50 people, representing a cross section of local community i.e. mental health professionals, councillors, representative of various agencies and the voluntary sector. Key points raised at the seminar are included in section 4.4.3.

2.3. Sample and Ethics

There was no set numbers for informal interviews or discussions, however prior to designing the questionnaire at least 4 focused discussions were held among the research

team, who were predominantly service users and key workers.. Around 50 questionnaires were completed by users, over the age of 16 (see section... for sample profile) and 25 professionals completed another specific questionnaire. It is estimated that in total over 250 people contributed to the research process in one way or the other, including members of the steering committee, cluster group and participants at seminars, and conferences, and one to one discussions.

Sample

Since there was no specific community or the known size to choose from, we could not follow random or cluster or quota sampling techniques. Therefore we heavily depended on snowball, purposive and opportunities sampling techniques to choose i) professionals who were willing to participate and give their views, ii) users who were requested to contribute for the sake of improving services and finding solutions for their problems and had some experiences to share. Any opportunity presented to researcher(s) in social gatherings, meetings, conference, were avail to chat to interested individuals and professionals on one to one basis.

All these sampling techniques were used in various data collecting methods that we used e.g. one to one interview were opportunistic, focus groups with users and key workers were purposive and the questionnaire were administered through snowballing.

Besides certain key steering committee members were very helpful in terms of giving appropriate information about accessing south Asian users at particular institutions and certain professionals who would be appropriate to contribute.

The focus group discussions were tape recorded and subsequently transcribed and analysed. The results are presented in Section 3.4.2.

The research team worked in pairs to get the questionnaires completed. Those informants who were able to complete the questionnaires themselves, they were requested to do so but those who could not adequately write, were read the questions by one researcher and other one wrote the answers.

Ethic committee approval

Once the approval from Uclan was granted, a separate request was made to the local Mental Health Trust Ethics Committee to seek their approval to access potential respondents and seek their guidance around risk management. They were provided with the both the final questionnaires approved by Uclan and the detailed ethic application form, which was submitted to Uclan Ethic Committee, along with a set of instructions which were prepared for the interviewers relating to ethics and other practical issues.(Please Appendix C – completed ethnics form)

Ensuring confidentiality and anonymity

Focus groups have different ethical considerations to one to one interview.

It is usually difficult to guarantee confidentiality to anyone taking part in a focus group, but participants were requested that people should keep views confidential, expressed in the group. They were informed that their views would be recorded and included in the final report under various themes, in order to draw conclusions and make recommendations, but the views expressed would not be attributed to any particular person by name. In a number of cases the names of the participants were known, but these were not recorded, to link their views to them, or to show who had participated in the research process.

Their names were not known or sought and personal details were not linked to any individual. They were not asked to sign the consent form. The names of participants/respondents were not revealed to anyone outside of the research team.

Interviews were conducted in private rooms within the Centre or any other appropriate place. Completed questionnaires were stored in a locked filing cabinet in an office within the centre. Only staff working on the project had access to them. If the questionnaire was completed elsewhere, i.e. not at the Qalb Centre site, then the researchers were required to transport the questionnaire back to the site as quickly as possible and kept in the filing cabinet. If transportation facilities were needed these were provided to the researcher, if public transport was deemed inadequate. The completed questionnaires were not left in the cars, brief cases or taken home by the researchers.

Data from the questionnaires were analysed and presented in the final report (and any interim reports) in such a way to ensure that it was not possible to attribute any particular response to any specific individual.

However the information sheet about the project and the introduction was read out and given to participants which explained to them (a) what the project was about. (b) that participation was voluntary (c) that the information would be used to make recommendations for improvement of services, and (d) that they could stop the interview at any time and (e) that they did not have to answer any questions that they did not want to.

Risk identification

There are risks involved to both the researchers and the respondents, e.g.

- The researchers safety and security
- Emotional distress caused to the respondents
- Distress caused to the researchers who are service users themselves
- Security and confidentiality of the data collected and keeping the information safe and secure
- Danger of working with violent patients
- Privacy and location of venue where data will be collected
- Consent by the participant to participate or withdraw at any time
- Ensuring anonymity

A number of opportunities existed to identify possible risks: individual workers identified them on their own; they identified as part of weekly team meetings; they identified during discussion with the support worker; they identified at Steering Group meetings. Where any risk was identified it was the responsibility of the Project Co-ordinator to ensure that measures were taken to manage the risk appropriately. The Research team was supported in doing this by the Support Worker, the coordinator and their own line management structure within the Qalb Centre offices.

Risk management

i) A confidentiality clause was established and ground rules were agreed within the team, Steering Committee and other individual and group meetings.

(ii) There was also the risk for researchers' safety which was managed by creating awareness about potential hazards and ensuring that they worked in pairs, particularly female researchers.

(iii) In order to control risks, the interviewers were not expected to visit homes of potential respondents for completion of questionnaires or to do with any aspect of the research project.

(iv) The consent form was read to the participants and they were assured about the anonymity.

(v) The Qalb Mental Health Centre had agreed to provide emotional support, free of charge, by their qualified therapists and counsellors in case of any emotional distress either to the participants or the researchers.

(vi) The Director of the Qalb Centre and the Manager of Fergusson Centre were asked to advise on how to approach the potential respondents, with particular reference to any violent history of the respondents. If it was considered advisable to approach such respondents then the researcher (s) were not allowed to work alone, in a close room. A suitable venue with clear exits was used for completion of the questionnaire. The session time was made known to the centre manager or whoever is in charge at the time. Issues around violence concerning certain mental health service users in certain situations were made known to the interviewer/ researcher.

(vii) If someone is known to be violent or dangerous, such respondents were not included in the list.

(viii) The research team was guided by the guidelines given by the local PCT/Mental Health Trust Ethic Committee about any local Mental Health Institutions.

(xi) Every effort was made to address the issues of safety and risk management to do with potential respondents and their conditions and the researchers, who themselves were service users.

(x) A special meeting of the team was devoted to the risk management before the team embarks on data collection. A four page guidelines and instructions were prepared for the researchers and whoever collected the data (See Appendix for the copy of guidelines)

2.4. Steering Committee

Before the research project commenced, a DRE Steering committee was already in existence. It was decided at their meeting in May, 2006, that the DRE Steering Committee will serve as a Steering Committee for the project as well.

At the request of the steering committee a special paper was presented to highlight the focus of the research and to link the work of the steering group with the work of the research project. At every six weekly meetings the project coordinator presented progress reports and sought further guidance from the members. A great deal of contacts was made via e-mail in between the six weekly meetings to check at every stage for the focus of the project. The Uclan Support worker was copied all this correspondence. Three particular members of the steering committee, who represented North East London Mental Health Trust on the Steering Group, took keen interest and guided what kind of information was required to contribute to their action plan. These individuals included the Community Development Worker, the Diversity Manager, and their Manager.

At the first meeting the following terms of reference, membership, and working rules were agreed.

{ 1 } To steer the research project and monitor progress to ensure it is conducted within its scope, timetable and that it adheres to the agreed objectives;

{ 2 } The members of the Steering group to contributed to the development and completion of the project by way of providing resources/material and carrying out tasks as agreed by the Committee and above all providing contacts to the research team to access potential respondents.

The role of steering groups

Steering Committee oversaw and supported (the 6th draft of the user questionnaire and 3rd draft of professional questionnaire: These questionnaires were circulated to the all the steering committee members for their comments: sent by the PCT i.e. the Steering Committee lead). Small group of steering committee members met with the coordinator face to face to go over the questionnaires and provide further advice regarding sample etc.

The Steering committee supported the request for getting ethical approval from NELMHT. The progress reports were presented and they also commissioned a report to articulate links between the community engagement project and the DRE agenda. The research coordinator, the Uclan support worker and the Director of the Qalb Centre had

access to all the information produced for the Steering Committee both by NELMHT and the PCT. (Please see Appendix for terms of reference and membership of the steering committee)

3. RESULTS

3.1. Introductions

In this section both quantitative and qualitative data is presented. Thematic analyses were carried out of the focus group discussions and half day seminar, both reported in Section 3.4. (Similarly thematic analyses were carried out of the literature review, particularly the 11 Community Engagement research projects carried out at pilot stage, reported in Section 1.7.) The quantitative data was analysed using Microsoft excel to produce tables and graphs, using frequencies and percentages.

Fifty service users completed a comprehensive questionnaire, comprising 42 questions, and thirty professionals completed a separate questionnaire, comprising 32 questions. Findings of both these questionnaires are presented Section 3.2. and 3.3. under various sub headings.

It has been indicated as appropriate if not all the respondents completed the questions or if there were more than one answer to a question.

3.2. Quantitative Data (Users' questionnaire – (Q.1-42)

Besides the core data, i.e. the characteristics of the users' sample, the results are presented under the following ten sub-headings:

- 3.2.1. . Perception of Mental illnesses, personal experiences, & contributory factors (Q.11-15)
- 3.2.2. Perception of Services, Support, & Treatment received (Q. 16-19)
- 3.2.3.. Asian Carers' Needs (Q.20-24)
- 3.2.4. Perception of Barriers (Q-25-26)
- 3.2.5. View of Improvements (Q.27-28)
- 3.2.6. Perception of Cultural Sensitivity and level and type of services received (Q. 29-32)
- 3.2.7. Perception of Asian specific fears and experiences of services received (Q. 33-34)
- 3.2.8. Views on the support after discharge and on recovery (Q.35-38)
- 3.2.9. 2010 Vision (Q. 39-41)
- 3.2. 10. Final comments (Q.42)

The figures have been rounded up e.g. 61.9. to become 62 and so forth. All tables and figures were numbered

3.2.1. Core Data: Sample (Q.1-10)

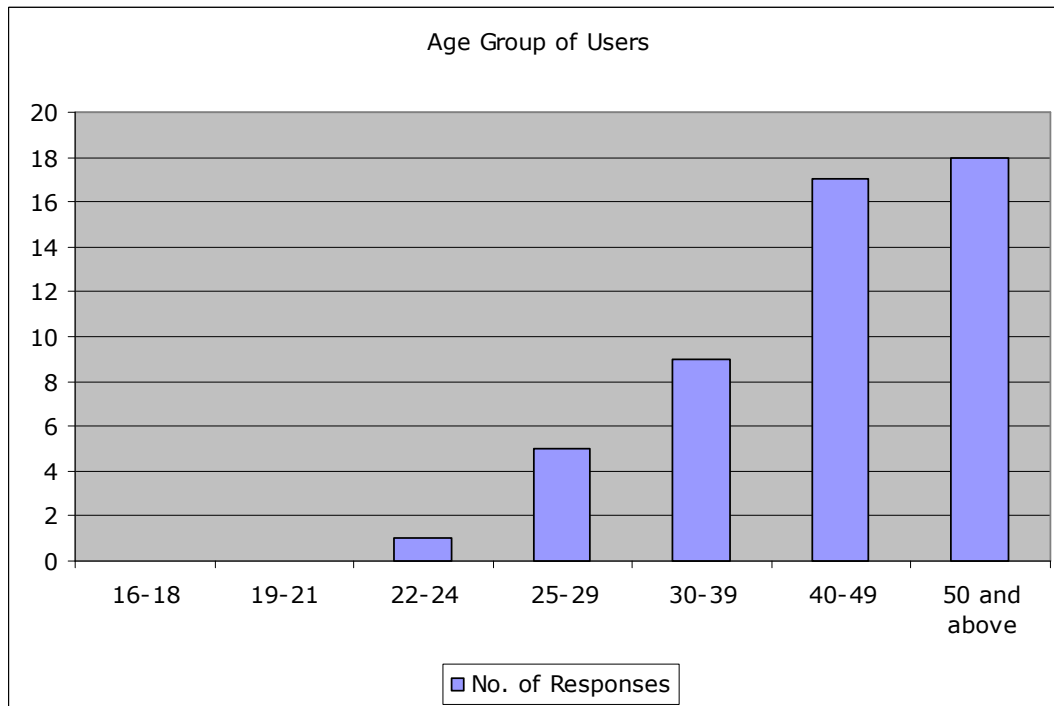
Our group was required to collect core data i.e. the sample profile. Ten questions were recommended by Uclan, which were included at the beginning of the questionnaire (s) the results are presented here under about the mental health users sample.

1. Age last birthday

Table 3: Age distribution

16-18	
19-21	
22-24	1
25-29	5
30-39	9
40-49	17
50 and above	18
Total	50

Figure 1: Age Distribution



2. Gender

Table: 4 Gender Distributions

Male	21
Female	29
Transgender/Transsexual	none
Total	50

3. Ethnic origin

Table 5: Ethnicity of participants

British	
Irish	
White and Asian	2
Caribbean	
African	
Sri Lankan	1
Indian	14
Pakistani	30
Bangladeshi	2
Chinese	1
Total	50

4. Were you born in the UK?

Table 6: Birth place of participants

Born in UK	No.
Yes	8
No	42
Total	50
How long have u lived here?	
Less than 1 year	
1-5 years	1
6-10 years	1
11 years or more	40

5. Citizenship

Table 7: Citizenship of participants

British Citizen	40
-----------------	----

6. Which is your first language?

Table 8: Mother tongue of participants

	Spoken	Written
English	9	21
Urdu	19	19
Hindi	2	
Punjabi	22	3
Bangali	2	1
Chinese	1	
Tamil	1	1

7. Which Languages are you fluent in?

Table 9: Languages: spoken/written skills

	Spoken	Written
English	29	24

Urdu	26	10
Hindi	6	4
Gujrati	3	
Punjabi	12	2
African Language	1	
Chinese	1	1
French	2	2
Singhalese	1	

8. What is your religion?

Table 10: Religions of participants (N=50)

None	1
Christian	1
Buddhist	
Hindu	4
Jewish	
Muslim	41
Sikh	1
Catholic/Muslim	1
Agnostic	1
Total	50

9. Would you consider your sexuality as?

Table 11: Sexuality of participants (N=50)

Lesbian	
Gay	
Heterosexual	48
Bisexual	
Transgender or Transexual	
Do not wish to answer	2
Total	50

10. Do you consider yourself to have a disability?

Table 12: Disabilities

Yes	32
No	18
Total	50

If yes, please specify

Table 13: Type of disabilities

<i>Mental Health</i>	26
<i>Diabetes</i>	1
<i>Not everyone responded</i>	

3.2.2. Perception of Mental illnesses, personal experiences, & contributory factors (Q.11-15)

11. How would you describe mental ill health in your own words?

- Mind is unwell, Madness, Mind not in control, Disorder concerning the mind, Pressure on brain, negative thoughts
- Doing abnormal thing: mood swings, can't sleep, wandering on the street, talking, crying, hearing voices, overwhelmed by thoughts.
- Challenges in managing normal everyday activities
- Being lonely & worried,
- Weakness, illness, health problem, not being well
- Depression
- Anxiety, Stress, Panic Attack, Confused, Crazy, Anxious, Withdrawn
- Being unable to cope
- Sense of doom, lack of domestic peace
- Shouting loudly at night
- Long term chronic Depression

12. Have you had any personal experience of mental ill health?

Table 14: Personal experience of mental ill health

Yes	44
No	3

Did not answer = 3

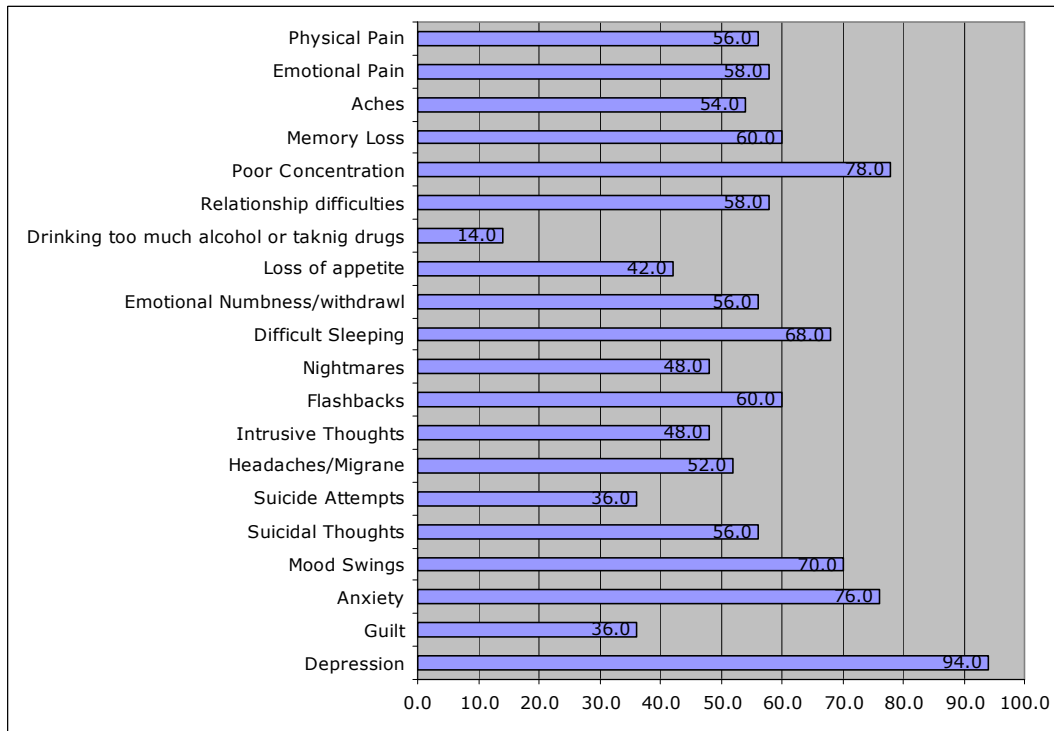
13. Have you experienced any of the following? (Please tick all that apply)

Table 15: Type of illnesses experiences (More than one response)

	%
Depression	94.0
Guilt	36.0

Anxiety	76.0
Mood Swings	70.0
Suicidal Thoughts	56.0
Suicide Attempts	36.0
Headaches/Migraine	52.0
Intrusive Thoughts	48.0
Flashbacks	60.0
Nightmares	48.0
Difficult Sleeping	68.0
Emotional Numbness/withdrawal	56.0
Loss of appetite	42.0
Drinking too much alcohol or taking drugs	14.0
Relationship difficulties	58.0
Poor Concentration	78.0
Memory Loss	60.0
Aches	54.0
Emotional Pain	58.0
Physical Pain	56.0
Other	
Panic Attack	

Figure 2: Type of illnesses experienced

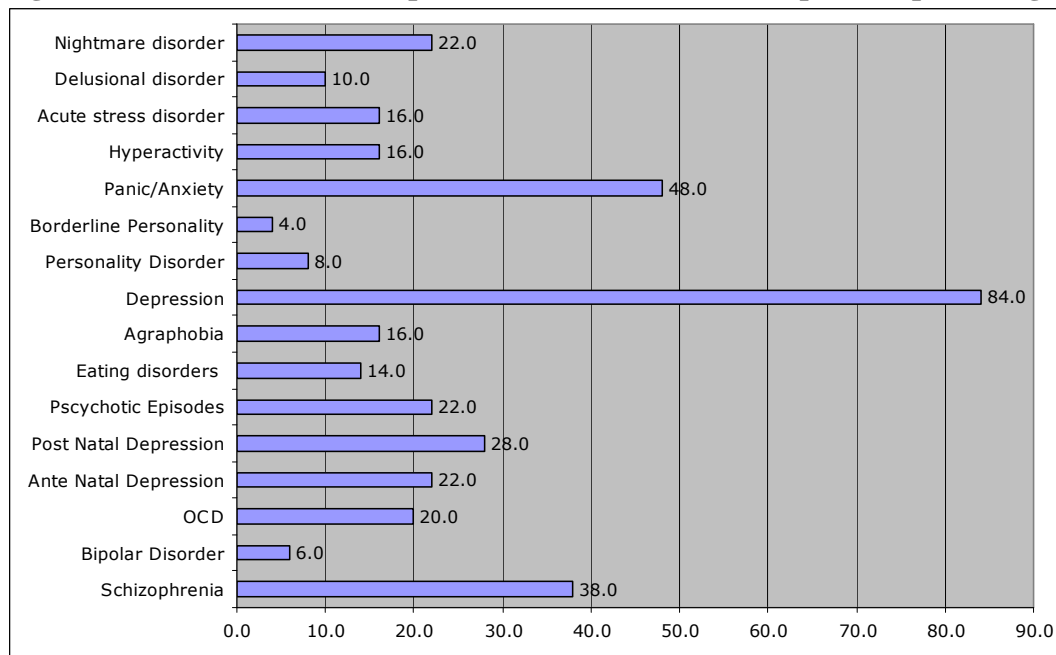


14. Could you kindly indicate which of the following conditions have you experienced?

Table 16: Named conditions experienced (More than one response)

	%
Schizophrenia	38.0
Bipolar Disorder	6.0
OCD	20.0
Ante Natal Depression	22.0
Post Natal Depression	28.0
Psychotic Episodes	22.0
Eating disorders	14.0
Agoraphobia	16.0
Depression	84.0
Personality Disorder	8.0
Borderline Personality	4.0
Panic/Anxiety	48.0
Hyperactivity	16.0
Acute stress disorder	16.0
Delusional disorder	10.0
Nightmare disorder	22.0
Any Other	

Figure 3: Named conditions experienced (More than one response) - percentage



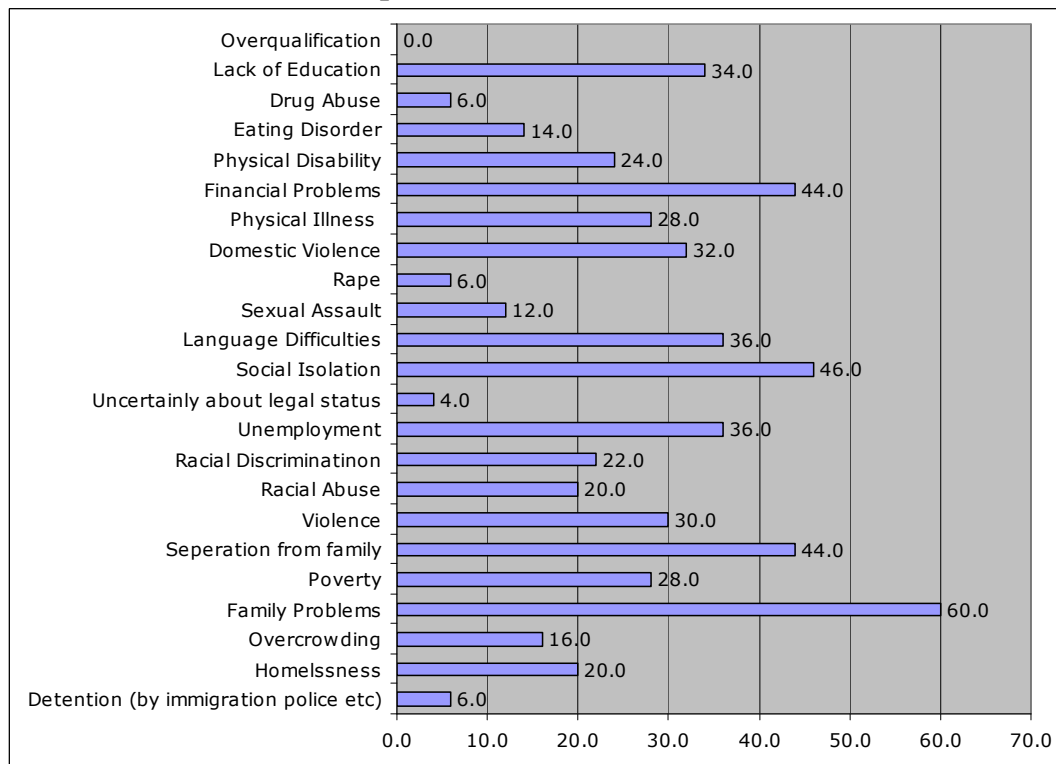
15. Do you feel any of the following factors may have contributed to your mental ill health? (In the UK)

Table 17: Perception of factors contributing to mental health (More than one response)

	%
Détention (by immigration police etc.)	6.0
Homelessness	20.0
Overcrowding	16.0
Family Problems	60.0
Poverty	28.0
Separation from family	44.0
Violence	30.0
Racial Abuse	20.0
Racial Discrimination	22.0
Unemployment	36.0
Uncertainly about legal status	4.0
Social Isolation	46.0
Language Difficulties	36.0
Sexual Assault	12.0

Rape	6.0
Domestic Violence	32.0
Physical Illness	28.0
Financial Problems	44.0
Physical Disability	24.0
Eating Disorder	14.0
Drug Abuse	6.0
Lack of Education	34.0
Over qualification	0.0
Other	

**Figure 4: Perception of factors contributing to mental health
(More than one response)**



3.2.3. Perception of Services, Support, & Treatment received (Q. 16-19)

16. Did you seek any support for your mental health issues?

Table 18: Whether sought support (Yes)

Yes	34
What kind of support?	
<i>GP</i>	9
<i>Family Friends</i>	2
<i>Came to Ferguson Centre</i>	
<i>Ferguson Centre, Qalb Centre</i>	4
<i>Hospitalization</i>	
<i>See consultant regularly</i>	
<i>Spend sometime in Stoneleigh</i>	
<i>Mom & Sis took me too out-patient, after I had a breakdown as a child</i>	
<i>Mum took me to hospital in Sirilanka</i>	
<i>Only after solitude and over-dosages</i>	
<i>Mum cared for me</i>	
<i>Went to GP, given medication</i>	

Table 19: Whether sought support (No)

No	16
Why Not?	
<i>did not know I had a problem</i>	
<i>transferred to Claybury</i>	
<i>went to GP</i>	
<i>felt I was no longer a useful member of society and was a less of a burden if I died</i>	
<i>I didn't know that depression can be a health problem</i>	
<i>I didn't know I had depression and didn't go to doctor, after a while I went to the doctor and he put me on anti-depressant but never told me</i>	
<i>Not wanting to admit, thinking I would get better</i>	
<i>Depressed, didn't want to</i>	
<i>I don't know</i>	2
<i>Didn't know I was unwell</i>	2
<i>Was too young, went to school counsellor</i>	

17. In which setting did you come into contact with mental health services?

Table 20: Contacts with services

Primary Care	74.0
Hospital Care	0.0
Stoneleigh	26.0
Nasebury Court	20.0
Claybury	20.0
Goodmayes	26.0
Specialist	54.0
Qalb Centre	54.0
Larkswood	16.0
South Forest Centre	34.0
Ferguson Centre	30.0
Other	
<i>Thornebury day centre</i>	10.0
<i>Truro Road Centre</i>	6.0
<i>WhipsCross</i>	2.0
<i>RFET Richmond Fellowship</i>	2.0
<i>Hawkwell Court</i>	2.0
<i>BPMH</i>	6.0

18. Your experience of using the services, based on?

Table 21: Type of experiences

Using service yourself	
Yes	39
No	
Caring for friend or relative	
Yes	3
No	8
Other	
Total	50

19. Overall, how would you rate the quality of your experience in these settings?

Table 22: Perception of quality of experiences

Very Poor	4
Poor	3
Average	14
Good	16
Very Good	13

Total	50
-------	----

3.2.3. Asian Carers' Needs (Q.20-24)

20. Are you caring for anyone with Mental Health issues?

Table 23: Whether a carer?

Yes	4
No	46
Total	50

21. Do you know anyone who is a carer or has cared?

Table 24: Whether knows anyone who cares?

Yes	12
No	37
Total	49

Did not respond - 1

22. What are the needs, if any, of a carer of a mental health service user?

Please Explain

- Carers should know of their own safety and treated with respect
- They should be provided respite
- Carer should have enough knowledge which they need in looking after the patient
- They should have manners: sensitivity, patience, understanding, non-judgemental
- Needs moral support, Outlets like Qalb Centre to send the user to - so carer has time for himself or herself,
- There is a need for Financial support for carers
- Getting support from community

23. Are you aware of any support one can get as a carer?

Table 25: Whether carers get any support?

Yes	6
No	19
Don't Know	10

Did not respond - 15

24. Can you describe how do Asian carers feel, if they have to care for some one in the family with mental ill health?

- Shame, keep it secret, blame, and deny that the mental ill health exists
- Very hard for them but they have to do what they can and are able to
- Very tired, upset, but feel it is their duty to do so
- They don't care how they should treat the patient. Some don't believe that the person needs help, so they ignore.
- Depressed, stressed, tired, confused, hard to cope, isolated, full responsibility so under pressure, anxious, un-settled.
- "My family still don't understand that mental health illness can be a proper illness"
- They do the caring out of love for other person
- They might feel they don't get help from other members of the family

3.2.4. Perception of Barriers (Q-25-26)

25. Have you experienced language barriers when receiving services?

Table 26: Experiencing language barriers

Yes	10
No	39
Don't know	1
Total	50

- Not able to explain problem while attended Hospital
- When I came to this country I could not understand English and couldn't explain my problems
- Always arranged to have someone with her
- When expressing feeling leads to misunderstanding, I don't understand difficult words
- In Stoneleigh I was unable to understand instruction
- When admitted to hospital always given injections and attacked by other patients
- When I went to GP or hospital I couldn't talk in English
- I could speak English, but had a speaking & hearing problem

26. Have you ever felt that you were treated differently because of your ethnicity i.e. religion, languages, culture, colour?

Table 27: Perception of differential treatment (N=50)

Yes	1
No	42
Don't Know	2
No response	5

Table 28: Who treated differently

By Staff	6
By System	4
By Other?	1

No responses = 39

Please describe the patterns and extent of such differential treatment

Table 29: Perception of extent and patterns of treatment

Very High	2
High	2
Some	6
Do not know	22

No response = 18

Have you experienced any of the following?

Table 30: whether experiences any specific treatments

	Yes	No	DK
Patronizing Attitudes	6	31	3
Lack of understanding about Asian value system	16	24	3
Verbal abuse (racial)	6	30	3
Physical abuse (racial)	5	33	2
Discriminatory treatment	4	33	3

Not all of them responded to all the questions

3.2.5. View of Improvements (Q.27-28)

27. Do you think enough is being done by local government agencies to improve? mental health services for the Asian Communities?

Table 31: Perception of level of support for Asians

Yes	24
No	16
DK	10
Total	50

If yes, what is being done?

- Meet at the Qalb Mental Health Centre
- Good medication, activities
- Support with benefits, bus passes, old people treated well, give council housing
- More help for DV, e.g Day Care Centre
- Those who don't work receive benefits
- There are many centre, hospitals and information places
- Was given house when had no home, shelter, hospital
- Specialist services for Asians
- Disability allowance, Larkswold regular checkups
- To my knowledge there are more Asian services now
- We have a centre that supports us
- Happy in Qalb Centre, happy with staff
- Both Asian community and Gov. agencies lack the confidence to integrate with each other
- Services are created for white people, lack of understanding of Asian culture
- They need to talk to Asian community

28. What other improvements can be made

- More structured activities to occupy the service users
- Could open more groups, exercise classes. Need more advice, help support. I have no idea about my rights and entitlements
- Provide help quickly. Language support
- Urdu radio, advertise about centres
- Staff attitude not good, especially by black staff, some black staff threatens. Staff should get into mental health for right reasons to serve users

- The staff should be trained properly for counselling and running day care centre. All patients should be asked if they have confidence in staff.
- They should appoint more Asian social workers or advisors, who are cultural/ethnicity sensitive. So they can give information to the ladies and they can try to sort out their own problems. Staff could be more helpful, giving advice, giving updates on mental health. Staff needs to understand different types of patients and how to deal with them.
- More information, more awareness, communication from social services
- I think GP's should be more knowledgeable about the mental health issues. So they can diagnose it early and its same for Asian, non-Asian communities
- More money in form of benefits
- More Asian Day Centres
- Good as it is

3.2.6. Perception of Cultural Sensitivity and level and type of services received (Q. 29-32)

29. Do you consider that the services, which you are receiving or have received, were culturally and religiously sensitive?

Table 32: Perception of culturally sensitive services

Yes	30
No	8
Partially	8
I do not know	4
Total	50

Could you kindly give reasons in support of your answer i.e. if yes, what was cultural and religious about them and how did you notice and if no, why do you say that?

Positive responses

- Can speak in our language, get our own food (Qalb centre user)
- Have separate areas in centre, where we can pray, and sit together, (Qalb Centre user)
- Meet with other Asian users and can talk in common language; Punjabi
- Qalb-Halal Food, Asian staff
- In hospital receive Halal food
- Should make people more aware of mental health centres, not for mad people, but less serious issues
- I didn't feel awkward
- Asian ladies don't know fundamentals and spirit of religion. With logic they should know the cause of our creation.

- Qalb and South Forest Centre is good, it's the language that makes me feel comfortable.
- Most asked for any cultural/religious need
- Get halal food, understand Muslim religion
- Not well treated. Shouting & verbally aggressive behaviour from staff who seek help
- Nobody spoke to me
- They spoke both languages
- Have a place for prayers, "halal" food for Muslims and vegetarians for those who need that.
- I asked for Halal food and it was give to me.
- I think they were sensitive to my religious needs
- Understood why I wanted to wear scarf
- Respect & understanding of all religion is taken care off in day care centre
- I have no religious needs
- BPMH sent me a Divali card, both day care centre, but they don't celebrate Divali, but they celebrate Christmas

Negative responses

- Jesus Christ and the Christian God were pushed as the real remedy to good healthfulness
- Not well treated. Shouting & verbally aggressive behaviour from staff who seek help
- Inpatient at Claybury, did not meet basic human needs, not fed her, kept her in a cold and dark room
- No body spoke with me

30. In your opinion what is the best treatment for you in the light of your conditions

Please Explain

- To seek special guidance from Allah
- How can I say anything about my treatment?
- No treatment for this condition
- Keeping to medication, taking it regularly
- Variety of activities, body centred work and psychotherapy
- Need to keep on going to Psychologist
- Positive support, positive counselling, that means not judging people and not forcing
- I had ECT treatment in India, but didn't do any good. I prefer tablet
- No treatment, just attend Qalb Centre, talk with other users
- I like coming to this centre (Ferguson)
- CPA meetings, C.B.T. Therapies
- Keep them occupied, busy
- Support them in things they enjoy.
- Psychotherapy, Good Meditation
- Peace of mind, avoid clashes with family
- Needed support from husband

- Love, communication, understanding,
- They should be informed of the knowledge they need and provide them own sources

Or do you consider the professionals know what is best for your mental health needs.

Table 33: Professional know what is best (N=50)

Yes	21
No	4
Sometimes	15
I don't know	5

Not responded =5

31. Do you feel comfortable disclosing your mental health issues to professionals?

Table 34: Whether would confide in professionals (N=50)

	No.
Never	7
Sometimes	15
All the times	12
Depends on the Situation	15

Did not respond=1

Please give reasons for the answer

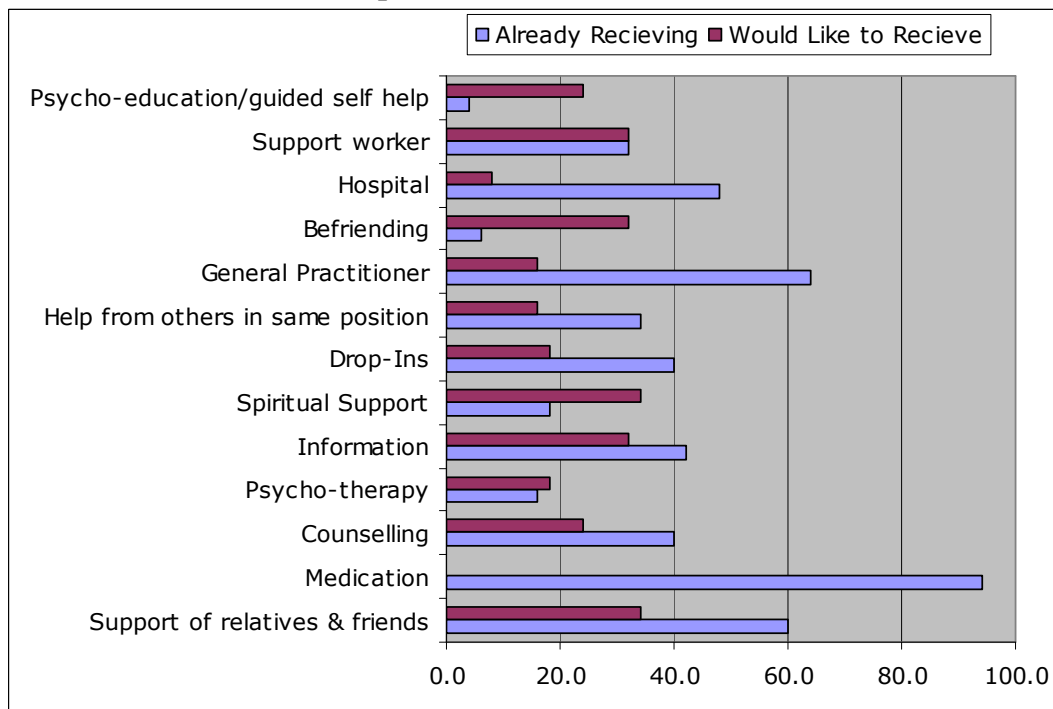
- Sometimes I panic, sometimes scared to share problem, other times I do fine
- Professional would already know about my situation before they approach me
- I am a shy person and am scared talking before others
- Could get irritated in residential mental health hospital. This would be very injurious to your health
- Not like sharing of problem by talking to other
- Having confidence in the other person and peace of mind
- I feel I am the only one with these problems
- I spent three years in hospital and there were a lot of group therapies. Plus I want to trust the professional.
- If I feel they understand me and there approach is sensible.
- Fear of speaking openly about it
- Sometimes it seems I am not aware of my depression, I like to isolate myself
- I can get close with professional and discuss all my illness.
- Scared of being put in mental hospital, having stayed once & got self discharged
- If I don't speak, how will anybody understand

32. Could you kindly indicate if you are already receiving the following and if not please tick what you would like to receive?

**Table 35: Type of services received or would like to receive
(More than one response)**

	Already Receiving (%)	Would like to receive (%)
Support of relatives & friends	60.0	34.0
Medication	94.0	0.0
Counselling	40.0	24.0
Psycho-therapy	16.0	18.0
Information	42.0	32.0
Spiritual Support	18.0	34.0
Drop-Ins	40.0	18.0
Help from others in same position	34.0	16.0
General Practitioner	64.0	16.0
Befriending	6.0	32.0
Hospital	48.0	8.0
Support worker	32.0	32.0
Psycho-education/guided self help	4.0	24.0
Alternative therapies		
Massage	18.0	42.0
Aromatherapy	10.0	30.0
Others (Please specify)		
<i>Reflexology</i>	34.0	8.0
<i>Nutrition advise for depression</i>	3.2	0.0
<i>Osteopathy</i>	3.2	0.0
<i>Art therapy</i>	3.2	0.0
<i>Homeopathy</i>	3.2	0.0
<i>Flower Remedies</i>	3.2	0.0

**Figure 5: Type of services received or would like to receive
(More than one response - %)**



3.2.7 Perception of Asian specific fears and experiences of services received (Q. 33-34)

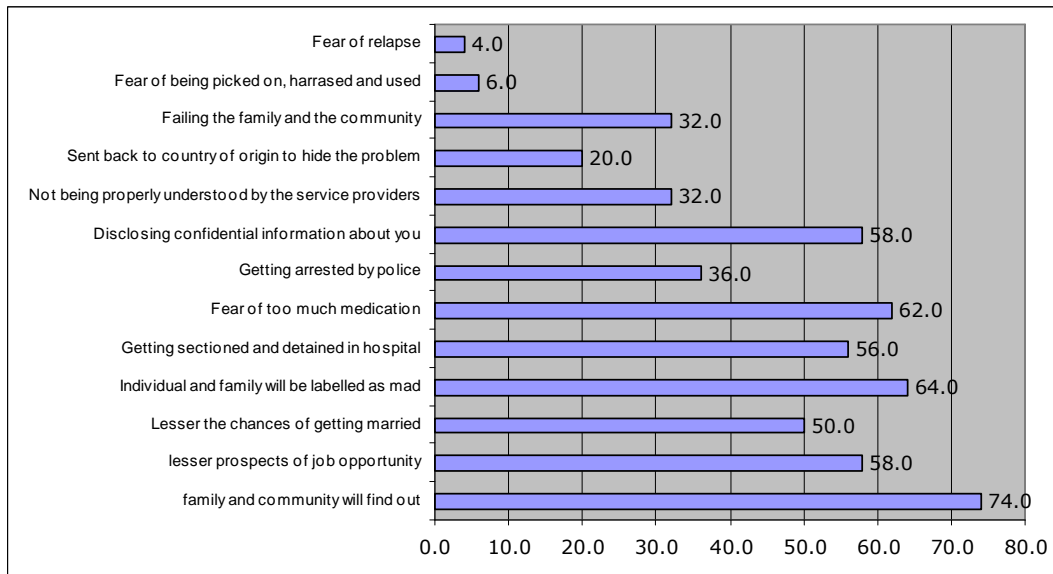
33. Asian communities have their own type of fears as listed below: Please tick if you agree and add any more

**Table 36: Asian community specific Fears (N=50)
(More than one response)**

	%
Family and community will find out	74.0
Lesser prospects of job opportunity	58.0
Less chances of getting married	50.0
Individual and family will be labelled as mad	64.0
Getting sectioned and detained in hospital	56.0
Fear of too much medication	62.0

Getting arrested by police	36.0
Disclosing confidential information about you	58.0
Not being properly understood by the service providers	32.0
Sent back to country of origin to hide the problem	20.0
Failing the family and the community	32.0
Fear of being picked on, harassed and abused	6.0
Fear of relapse	4.0

Figure 6: Asian community-specific fears (More than one response - %)



34. Could you describe your experiences of the care and services you received at following stages: (applicable to users/carers only) by putting a circle around

Table 37: Experiences of various services received (N=50)

	Bad	Very Bad	Good	Very Good
Referral by GP or any other source	6	4	30	10
Diagnosis and assessment	5	6	30	9
Type of treatment received	8	5	27	10

3.2.8. Views on the support after discharge and on recovery (Q.35-38)

35. Could you describe the type of help/treatment you received when discharged (On CPA)

- Not forced to stay as inpatient, could go home, not admitted
- Never went to mental hospital or being admitted after discharge
- Medication, Qalb Centre, checkups
- Referred to Ferguson Centre
- Very good
- For many years a social worker was assigned to me. I also attended drop in
- Sent to a group home against wish, not given a choice
- Put on medication, Injections, "to black people" mental health
- I didn't get any
- I received good home treatment
- Sent to work by Husband
- Key worker visit
- Sent her to house, visited by Nurse (nice), YMCA bad experience, Thorpe Court GP good
- Family sent me to Pakistan then I returned and stayed in bed & breakfast place and had no money, no where to go, left walking in the street
- Referred to Qalb Centre, Medication & Support from Qalb
- At Stonleigh Inpatient, not treated well, not respectful, not discharged at time
- Live in residential home, with others after coming out of Goodmayes, took me to a hospital in Scotland Somewhere
- Injection and tablet return home
- Psychology, counselling
- Didn't get help, asked Dad to get her discharged from hospital
- Never went to hospital. GP referred to Ferguson Centre
- Medication, Sent home, Referral to day care centre

36. Were you satisfied with the facilities provided after discharge?

Table 38: Satisfaction level with services after discharge

Yes	25
No	
I didn't know my options	13

Did not respond =12

If Yes, why

- I had panic attack, when they were about to admit me, I didn't want to so they let me go home
- See a CPN at Larkswood
- Social worker did house visits
- Going to Qalb centre, able to talk to community people
- Received home visits by different social workers
- Can socialize
- Feel more confident and can socialize too
- Council Flat, Drop-In, Social Worker
- Good medication, good contact
- Husband was helpful - Cooking & Cleaning
- I had the proper level of support
- Felt I was being well looked after
- Able to talk to other users
- Treatment in hospital was very good, staff good
- They were quite satisfactory, kept me busy
- Sewing classes, outings

If No, why not

- After care was not readily available
- I am in-patient
- They left me alone
- My needs as an Asian were not catered for

What could have been done differently?

- Applied for DLA, but was refused, needed some financial help
- Angry against the hospital. Sectioned against will, some 21 years ago, did not receive any help support with OCD. Needed more help, if I got it earlier, I would have improved
- They should have sent me back to my original country to be with my family & friends
- Needed interpreter, Muslim social worker

37. Do you think it is possible to recover from mental illness?

Table 39: Views on recovery (N=50)

	Yes	No	Sometimes
Can Recover fully	10	16	24
Can recover partially	21	5	24
Can recover never	10	12	28

38. How can you tell if some has recovered from the mental illness (Could please list some signs of recovered conditions

Table 40: Signs of recovery

<i>I don't know</i>	4
<i>Look normal, go about daily life and handle family affairs</i>	4
<i>Doing everything well, eating well, sleeping well</i>	2
<i>From the face you can tell; weak, from the way he walks</i>	
<i>Change in behaviour talking more</i>	
<i>Able to do things for themselves, without having to be asked, carry out due or more tasks t one time and talk and converse with others</i>	
<i>change in behaviour, taking charge, eating well</i>	
<i>they are looking better</i>	4
<i>talking normal, from face, they look changed</i>	5
<i>Happy</i>	3
<i>Thinking positively,</i>	
<i>If you can compare them with other people who are not diagnosed and are healthy</i>	
<i>to go back to work, not to stay isolated, get busy</i>	
<i>when your heart and mind is at peace</i>	
<i>Looking relaxed, smartly dressed, not smoking, hair combed</i>	
<i>Happiness</i>	
<i>Don't know</i>	
<i>Peace of mind</i>	
<i>Thinking straight, look calm</i>	
<i>Be Normal</i>	
<i>Not taking medication anymore</i>	
<i>Feel happy, mood is good</i>	

Not everyone responded

3.2.9. 2010 Vision (Q. 39- 41)

39. If mental health patients are involved with the police, it is believed, they end up in prison:

(The respondents were given the following four options (see Table 41 below) to answer this question. Ideally they should have been, perhaps, asked: “What happens to the Mental Health patients if they are detained by the police or involved with the police” and then different options should have been given e.g. they end up in prison, or they are referred to hospitals / doctors or given appropriate care or support).

However the national statistics show that once mental health patients get in contact with police, they invariably end up in prison, hence one of the DRE targets to avoid that happening or reducing the numbers in prisons)

Table 41: Perception of police and mental health patients (N=50)

Yes	4
No	14
Not Always	24
<i>Don't know</i>	8
Total	50

40. If yes: how could this be avoided and reduce the numbers in prisons:

(Although only 4 respondents said 'yes', those who said 'no' and 'not always' also gave their views voluntarily on how to avoid mental health patients 'ending in prisons', if involved with the police e.g. *if police knew they were ill, they would put them in hospital.*

- Put them in mental health hospital, make sure they recover fully
- Should be taken care of in a loving, warm, caring environment
- Don't let them out unaccompanied
- Refer them to their doctor
- If police knew they were ill, they would put them in hospital
- Police could be more understanding
- Dedicated support care
- Get people to attend centres, be gentle
- Maybe they could get more support, maybe they need help
- The should be sent somewhere else, depends on their needs, how they feel like hospital treat them well

41. It is generally believed that BME mental health patients are given more drugs than other therapies. Do you agree with this?

Table 42: Perception of range of therapies (N=50)

Yes	11
No	9
DK	30
Total	50

If yes, why do you think it is?

- I feel that African culture is not understood properly
- Not spending much time with patients
- They don't want people progress
- White Staff, Hindu, Sikhs, jealous of Muslims
- If person gets happy they can recover
- Therapies are more costly

- Because of their colour
- Black people more powerful, more violent

Since 'BME mental health patients' was mentioned in the question, instead of South Asian, it is not surprising that South Asian respondents referred to 'African Culture' and 'Black people being more violent', in their responses.

And what other culturally appropriate services could be provided: Please list the range of treatments and therapies, which would help

- Meditation, psychotherapy, CPN
- Arranging cultural activities, understanding cultural social system of Asia
- Go out for outing with fellow Asians
- Counselling and groups work
- Invitation to other centre
- GP should have mental health professionals coming over regularly
- We bring troubles to ourselves, bodies and this effectively kills us, leaves us dead
- Asian befriender. The counsellor who is from back home and not born here.
- Staff gets understanding of patient, need to company with someone from same background.
- More help, language, exercise equipment, need awareness of services
- More help with independence
- More 1-1 counselling, regular help with a therapist, to get the person back to normal.
- Places like Qalb Centre in more areas
- Speak to her more, help in separating from her husband, give her place to live with other Asians
- Many already are very useful, come to centres, join in groups, Activities, Swimming, Art & Craft, Watching videos so they don't go out and be with other people
- Anything that could help,

3.2.10. Final comments (Q.42)

42. Would you like to add any thing else which has not been covered so far?

- People need to recover fully for the family sake so that they can cope with day to day life.
- Did not know about some of the abbreviations used
- My other social gathering is going to mosque
- They need education about facilities, and also how they can live better, and how they can solve own problems.
- Want Qalb to remain open continuously, visit other centres, interesting places, 1to1 therapy counselling and increased awareness of choice of treatment available
- I want to go back to Mauritius
- Need help from social worker visit

- She was disturbed as she was put in a white neighbourhood; they were fighting with her all the time
- Sometimes you have to be willing to explore more options and more paths

3.4. Quantitative Data (Professional Questionnaire 1-33)

As was mentioned in the previous section, here as well besides the sample characteristics, the results are presented under the following sub-headings:

- 3.4.1. Core Data (Professional Sample Q.1 – 6)
- 3.4.2. Perception of various factors contributing to mental ill health and patterns of mental illnesses. (Q.7-9)
- 3.4.3. Perspective on Caring in the Family (Q.10 – 14)
- 3.4.4. Perspective of Culturally competent services (Q.15-18)
- 3.4.5. Awareness of and attitudes recommendations of various reports (Q.19.20)
- 3.4.6. 2010 Fit for Purpose (Q.21 – 33)

3.4.1. Core Data (Professional Sample Q.1 – 6)

1. Gender

Table 43: Gender – Professionals (N=30)

	No.
Male	10
Female	20
Total	30

2. Ethnic origin

Table 44: Ethnicity Professionals (N=30)

British	7
Irish	2
European	
Caribbean	
African	5
Somali	
Indian	7
Pakistani	3
Bangladeshi	2
Chinese	
Mauritian	2

Arab	1
Black British	1
Total	30

3. Linguistic Skills

Table 45: Linguistic Skills – Professionals (More than one response)

3	Which Languages are you fluent in?	Spoken	Written	Reading
	English	1		
	Urdu	10	1	1
	Hindi	5	1	2
	Ibo	1		1
	French	5	4	4
	Mauritian	1	1	1
	Bengali	2	1	1
	Arabic	2	1	1
	Tamil	2	1	1
	Yoruba	1	1	1
	Gaelic	1		
	Cantonese	1		
	Afrikaans	1		

4. What is your religion?

Table 46: Professionals’ religious background (N=30)

None	5
Christian	9
Buddhist	
Hindu	3
Jewish	
Muslim	12
Sikh	
Everything	1
Total	30

5. Name of your agency/Department/Institution e.g. Goodmays Hospital or name the Vol. organization (or preferred provider etc.)

Table 47: Names of professionals’ organisations/institutions

Name of Agency/organisation	
<i>Ethnic Rehabilitation Services - Waltham</i>	1

<i>Forest</i>	
<i>LBWF - Community Services</i>	1
<i>NUMIFI</i>	2
<i>LBWF</i>	2
<i>NELMHT</i>	2
<i>MIND</i>	2
<i>Voluntary Organisation</i>	2
<i>Whips Cross Hospital</i>	2
<i>Qalb Day Care Centre</i>	6

Not everyone responded

6. Your role or job

Participants were asked to identify their specific job title and their roles.

Not all the participants responded fully. However those who responded showed that a range of professionals of mental health services participated in our study. Those who gave their job titles included:

- ▶ Psychiatrists
- ▶ General Practitioner
- ▶ Clinical psychologists,
- ▶ Counsellors
- ▶ Psychiatrist Nurse
- ▶ CPN
- ▶ Key Mental Health Workers
- ▶ Group workers
- ▶ Asian Befriending Worker
- ▶ Rehabilitation worker
- ▶ Services Managers
- ▶ Project Director
- ▶ Volunteers
- ▶ Voluntary Services Coordinator
- ▶ Supervisor of the Services
- ▶ Incharge of operations

They were also asked to indicate whether nature of their job included any of the following: *(15 did not respond)*

- ▶ Policy development = (4)
- ▶ Training / recruitment = (3)
- ▶ Face work = (7)
- ▶ Any other (Rehabilitation = (1)

3.4.2. Perception of various factors contributing to mental ill health and patterns of mental illnesses. (Q.7-9)

Based on the literature review and from the preliminary discussions it was felt that perhaps there were certain issues which were specific to the Asian communities, compared with the rest of the population. Therefore some of those factors were identified and grouped under five ‘different environments’. The respondents were asked to endorse whether they concurred with the proposition. They were asked to rate their responses on a five point scale – **5 being the highest level of endorsement and 1 being the lowest (i.e. 5 denoting greatest level of influence as a factor)**

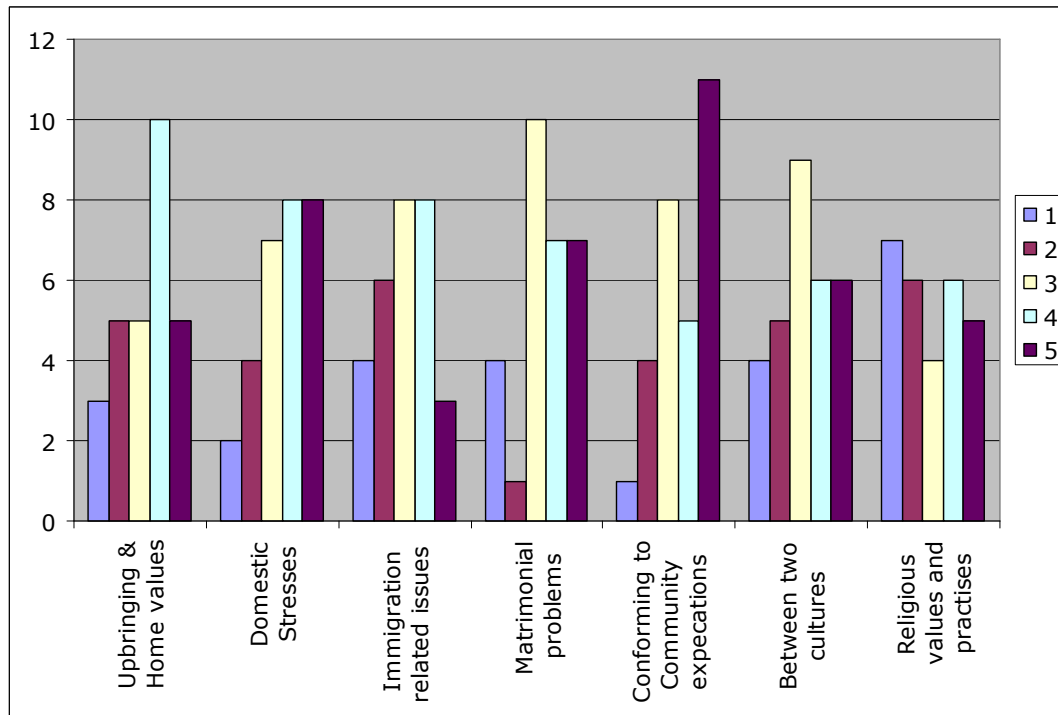
7. According to your analysis could you kindly state whether any of the following factors tend to contribute proportionately more, compared with the rest of the population, to the mental illness of the South Asian mental health service users

3.4.2.1. Their home environment e.g., (7 factors)

The following seven factors were explored:

1. Upbringing and Home Environment
2. Domestic stresses
3. Immigration related issues
4. Matrimonial problems
5. Conforming to community expectations
6. Between two cultures
7. Religious values and practices

Figure 7: Effects of Home Environment on Mental Ill health (%) (5 being the highest)



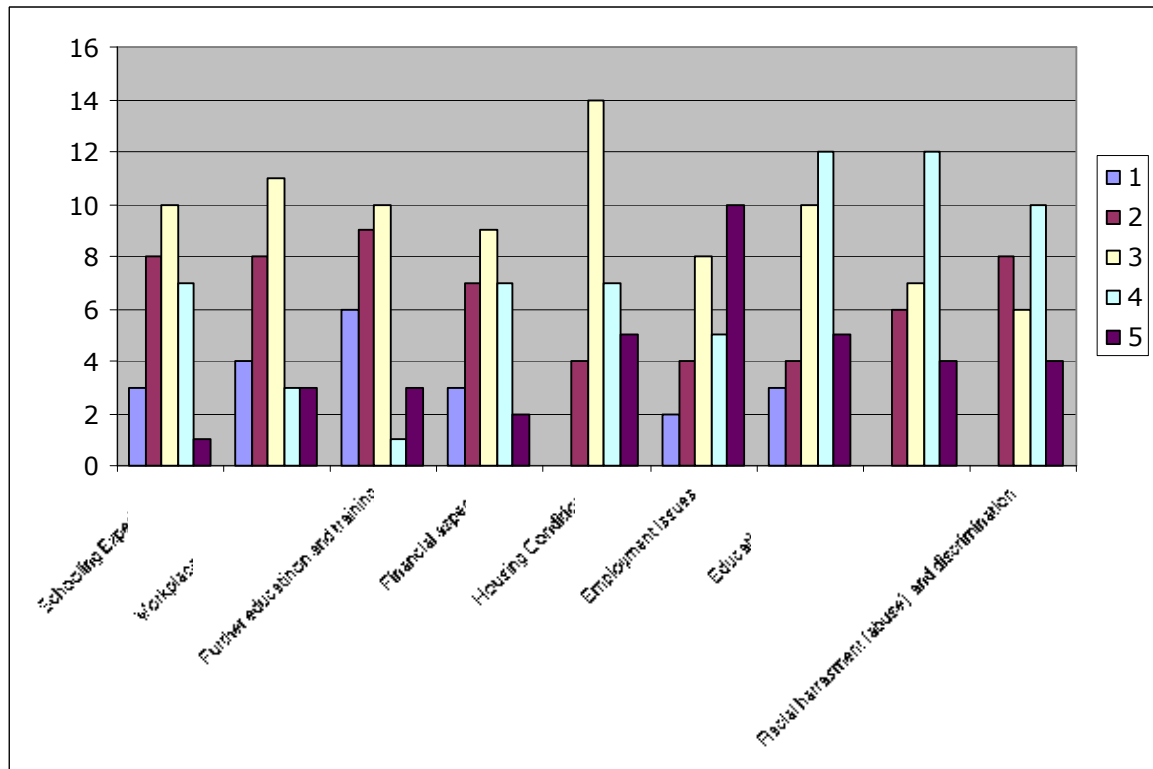
Average Ranking (%) for factors related to Home Environment

3.4.2.2. External Environment

The following nine factors were explored:

1. Schooling experiences
2. Workplace experiences
3. Further education and training
4. Financial Aspects
5. Housing Conditions
6. Employment / unemployment / underemployment
7. Education level
8. Racism and Discrimination
9. Racial Harassment (abuse) and discrimination

Figure 8: Effects of External Environment on Mental Ill health (5 being the highest)



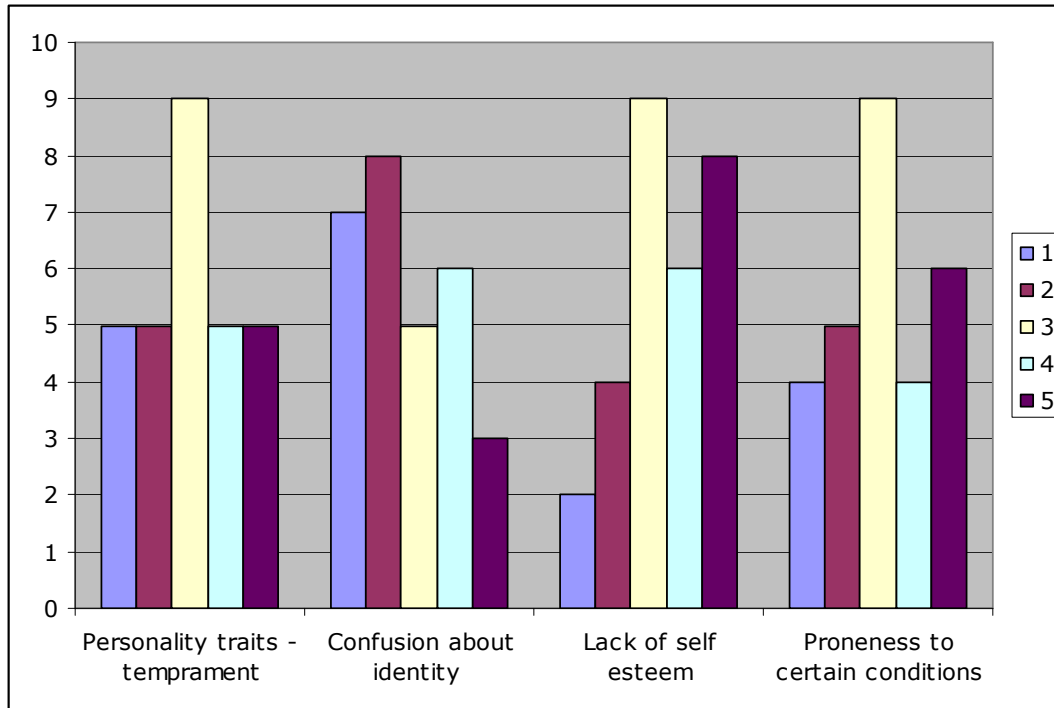
Average Ranking (%) for factors related to External Environment

3.4.2.3. Internal Environment factors - Socio –psychological

The following four factors were explored:

1. Personality traits – temperament etc.
2. Confusion about identity
(E.g. whether British/Pakistani/Indian or both or any other)
3. Lack of self-esteem / self image and self confidence
4. Proneness to certain conditions

Figure 9: Effects of Internal Environment on Mental Ill Health (%) (5 being the highest)



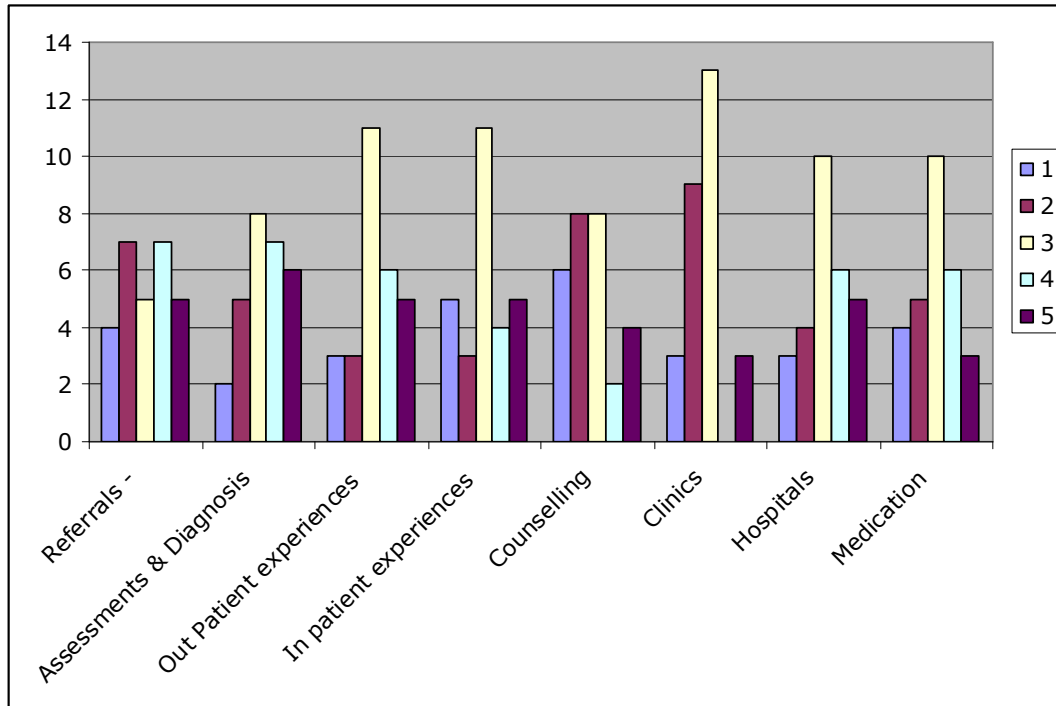
Average Ranking (%) for factors related to Internal Environment

3.4.2.3. Treatment Environment

The following eight factors were explored:

1. Referrals – GP etc. the manner it was dealt with
2. Assessment and diagnosis
3. Out patient experiences
4. In patient experiences
5. Counselling
6. Clinics
7. Hospitals
8. Medication

Figure 10: Effects of Treatment Environment on Mental Ill Health (%) (5 being the highest)



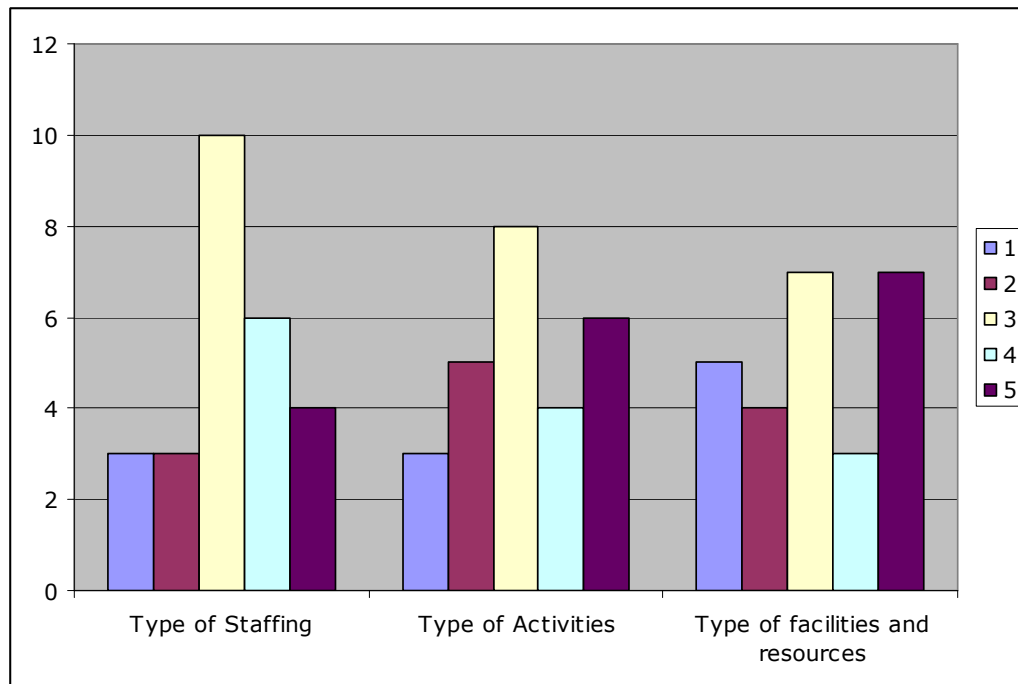
Average Ranking (%) for factors related to Treatment Environment

3.4.2.4. Day Care and Rehabilitation Environment

The following three factors were explored:

1. Type of staffing at the rehabilitation centres
2. Type of activities – whether cultural sensitive
3. Type of facilities and resources – cultural /religious sensitive

Figure 11: Effects of Day Care and Rehabilitation Environment on Mental III Health (%) (5 being the highest)



Average Ranking (%) for Factors related to Day Care and Rehabilitation Environment

8. Could you also list any factors / aspects which are specific to Asian cultures, religions and languages that might help recovery?

- Good Education, Proper living environment, Family Support, Financial Support,
- Family Outings, Social Engagement, Parent education, Getting on with all members of family, dealing with children suffering from mental health
- Trusting Relationships, If wanted culturally sensitive services
- Religion, Community Support, Cultural Practices, Culturally competent staff/nurses, Family Support, MH promotion, Dealing with language Barriers, Sensitive to Asian Culture Recognition of faith, incorporating faith/culture in treatment, understanding cultural identity
- Family Closeness, Religion/Cultural, Community
- Employment
- Lack of Domestic Violence

- Empowerment
- Respect for religion
- Getting involved early
- Settling in work
- Educating Community
- Better Communication
- Build cultural awareness
- Belief in their religion
- Speaking to counsellor in their mother tongue

9. In your opinion are there any specific patterns of mental illness among the Asian communities e.g. certain types of disorders and mental illnesses more common among the Asians than other groups

Table 48: Perception of specific patterns of mental illnesses (N=30)

	No.
<i>Yes</i>	8
<i>No</i>	5
<i>Don't Know</i>	10
<i>Did not respond</i>	7
Total	30

If yes,

- Drug induced Psychosis
- Alcohol Problem
- Acculturation Process
- Depression

Could you explain, why this could be so

- Getting married with their own blood relations
- Clients have to deal with expectation of two cultures
- No mental illness is more common among Asians
- Not sure, there are patterns but stress & pressure may exacerbate anxiety, depression & OCD more.
- Stresses
- Family, culture, roles & expectations of the culture
- Mostly depression caused by moving to another country

3.4.3. Perspective on Caring in the Family (Q.10 – 14)

10. What are your views about the quality of caring for users of mental services within the Asian families?

- Parents don't have any idea how to deal with such situations
- Strong family support.

- Sometimes lack of opportunity to be independent.
- They are fairly well cared for and they often receive the services they need
- Close support, good quality of caring from Asian families
- Educating & supporting the family is pivotal to the well being of the client
- I think the close knit families are a help but can be daunting especially in the case of psychotic patients
- Supportive
- Adequate
- Over protective,
- Low quality, Very Poor, Not very good
- Lack of knowledge /awareness on mental health could prevent families to understand the nature & extent of support required
- Because of the cultural backgrounds women and children end up doing most of the work
- Differs according to the family, but generally good once they admit problem exists
- Would be improved if approaches were used that were conducive & specific to their cultural needs, as with many cultural groups
- Better than other due to extended families
- Lack of information
- Lack of services due to large number suffering from mental health

11. What are the needs, if any, of an Asian carer of a mental health service user

- Same as all carers but also community support that is culturally relevant
- He/She needs emotional support
- They need financial support
- Needs Assessment is essential support by staff, Culturally sensitive towards carer by staff & MH professionals
- Understanding the expectations & needs of the carer
- Interpretation of Legislation/Mental Health Issues
- Recognition of cultural barriers
- Reassurance, Hope, Understanding,
- Education, Carer Support Group: Develop knowledge/awareness on different types of mental health(in their own language if they can't speak English) as well as support groups
- Support services: respite for carers, to relief them of mental overload
- They need to integrate to share experiences and remove isolation
- Early introduction to work – expectations and what support is available
- Language skills and understanding of culture
- Day Centres
- The needs of carer are met by NHS

12. Can you kindly describe the kind of support available to the carers generally?

- Carer Support Group
- Generally same as for everyone else - Day hospitals, CHB, Care coordination

- Counselling, supplementary therapy and benefit: Respite care, day trips
- Support Groups
- Information
- GP support
- Social work - generally lack of information
- Some support groups - very little generally, at present: Could be better

13. Do you think Asian carers are accessing the support, they need?

Table 49: Views about Carers accessing services (N=30)

	No.
<i>Yes</i>	6
<i>No</i>	11
<i>Don't Know</i>	8
<i>Did not respond</i>	5
Total	30

- It is very difficult to explain and make them do anything
- There are resources like carers support which some access
- Asian carers not informed about support available
- Due to stigma they shy away from mental health services
- Not really
- Because Asian tend to not integrate, there is much mis-understanding and confusion
- Lead a busy life, not aware of services
- I think they are not, as information which should be available and welcoming, but it is not.

14. In your view, how do Asian carers feel if they have to care for some one in the family with mental ill health?

- They refuse to accept mental illness: A level of denial and shame exists amongst them
- I think they feel overwhelmed and burdened due to support deficiencies.
- Pained to the core and level of loss
- They feel concerned and sometimes this can be overbearing
- Feel Okay but unable to access services due to language barrier and unprepared
- Depends on the individual
- Isolated
- They feel drained unsupported and unable to cope mentally themselves
- Pressured, needing to live up to expectation
- Often frustrated due to not understanding the problem and not being able to find the proper channels for help
- I have not been directly involved with Asian carers
- Same as anybody else
- Stressed, Anxious

- There is sense of duty to care, Pressure to please the family, Guilt

3.4.4. Perspective of Culturally competent services (Q.15-18)

15. Could you kindly describe in your own words a culturally competent mental health service provision relevant to the South Asian communities?

- There is not a competent mental health service provision relevant to South Asian Community
- Culturally competent facilities, provision of food/prayer rooms. Supported by staff with awareness/sensitivity
- Qalb: on the surface only appears to be used by Muslim clients, only two Hindus
- Qalb centre is a local service, but it is not a mental health service provision as such. Moreover it caters for predominantly Muslim mental health service users.
- Effective use of EOP's in service delivery + recruitment practise, Empowerment strategies/ direct involvement
- A team with some Asian workers who can work and understand the cultural issues and feed back to team
- The one in use now seems competent
- Don't know
- A service client is geared to understanding the practice in client culture taking into consideration, sensitivity and environment
- Doesn't matter as long as they are introduced to early normal working life
- Can't answer it, don't know country background
- One that meet needs of the south Asian individual, Have counsellors that have understanding & knowledge of various religions and cultures

16. Do you consider that the services provided by NELMHT are culturally competent?

Table 50: Perception of cultural competence (N=30)

	No.
<i>Yes</i>	4
<i>No</i>	2
<i>Somewhat culturally competent</i>	6
<i>I don't know</i>	13
<i>Did not respond</i>	5
Total	30

Could you kindly give reasons in support of your answer i.e. if yes, how and what and if no, why not?

- Language barriers, parents are not educated; do not recognize mental health as illness
Lack of provision/resources. Resources not translated, lack of culturally sensitive/linguistically sensitive psychological support

- I know there is a cultural CPN but feel there is room for improvement
- Are any of the services competent?
- Not enough Asian workers to support the clients and carers needs
- I have heard nothing to persuade me otherwise
- Don't know
- All clients are treated the same and given the same support and service
- On visiting special centre, the question of cultural awareness was discussed briefly
- More resources could be made available to enhance existing services
- I think services providers are meeting needs otherwise users not use NELMHT

17. These days there is a great deal of emphasis on “values based practice in mental health”. Do you consider that there any specific considerations for “Asian values and belief systems” in this context.

Table 51: Implications for values based practice (N=30)

	No.
Yes	7
No	4
I don't know	15
Did not Respond	4
Total	30

Please give reasons for your answers

- There are values for South Asian and respect as well, i.e., different approach, special need
- The community are provided with prayer rooms and diet considerations are always considered.
- Asian value is based on the religious practise of the individual; how can the services, deliver culturally sensitive services
- Asian values are quite diverse, and rooted in different religions, so MIND THE GAP
- Need cultural training relation to Asian background
- Culturally appropriate staff if possible
- The mental health system should not be specific to any certain culture but to have a normal standard of values of this country

18. Do you agree that the Asian communities are reluctant to share culture specific and domestic issues and information with mental health professionals?

Table 52: Views about Asians’ reluctance to share Information

	No.
Yes	6
No	3
Sometimes	11
I don’t know	
<i>Did not respond</i>	<i>10</i>
Total	30

Please give reasons in support of your answers.

- They try but it’s very hard to get the true story out of them
- This is due to the individual being treated as outcast within the community
- Lack of understanding MH professionals, stigma, and confidentiality issues
- Too shy and shamed to discuss issues
- Embarrassment and difficulties in explaining personal & sensitive issues with others
- Shame
- The response from the Asian client is as good as if the mental health professional understands
- Fear of member of families being informed of details
- Due to lack of trust
- Due to upbringing, cultural background and non-integration
- Generally the community can be closed towards foreign element
- With any therapeutic relationship, the individual needs to feel trust before disclosing information
- If user feels comfortable
- It depends on the individual. However there has been a progression where Asian communities, or people in this community are being open about domestic issues, Older generation are maybe more reluctant to discuss such issues
- All the patients that I meet relate well with me
- Any understanding of mainstream services procedure

3.4.5. Awareness of Inside/Outside report and views about its recommendations (Q.19.20)

In section 3.4.3. a number of key drivers for the *DRE* have been mentioned, including ‘**Inside / Outside**’ report, which was published in March 2003. This report sets out three key objectives and recommendations i.e. (i) to reduce and eliminate ethnic inequalities in mental health service experience and outcome; (ii) to develop the cultural capability of mental health services; and (iii) to engage the community and build capacity through community development workers. Participants were asked about the existing of this key driver and they were asked to give their views about the key recommendations.

19. Are you aware of the Inside Outside Report?

Table 53: Whether aware of Inside Outside Report

	No.
Never heard of it	19
I have heard of it	6
I am addressing the issues in the report	2
Do not know what is in the report	3
Total	30

19. (A) The plan proposes that training of staff on cultural awareness and competency is an important goal. How do you rate this goal?

Table 54: Views on importance of cultural awareness training

	No.
Not Important	
Fairly Important	4
Important	4
Very Important	18
Don't know	4
Total	30

19. (B) The plan proposes a number of changes to be sensitive to ethnic differences in the care and services delivery. How important do you feel these changes are?

Table 55: Views on changing services to be culturally Responsive

	No.
Not Important	2
Fairly Important	6
Important	8
Very Important	13
Don't know	1
Total	30

19. (C) The plan proposes that black and minority ethnic communities themselves need further help.

Table 56: Views on self help to improving conditions

	No.
Not Important	3

Fairly Important	4
Important	7
Very Important	14
Don't know	2
Total	30

20. Overall, do you feel that the plans, if put in action, will improve mental health services provision for minority ethnic communities.

Table 57: View on putting plan into action for improvement

	No.
Yes	22
No	
DK	8
Total	30

3.4.6. 2010 Fit for Purpose (Q.21 – 33)

One of the key elements of DRE is the ‘12 characteristics’, i.e. the targets to be achieved by 2010. They were asked whether they knew about this very important five year plan and their views were sought about achieving these targets.

Table 58: Awareness about DRE (N=30)

	No.
<i>I have not heard about DRE in Mental Health Care</i>	18
<i>I have heard about DRE in Mental Health Care</i>	5
<i>I am not sure what is in DRE in Mental Health Care</i>	6
<i>I am involved in implementation of DRE</i>	1
Total	30

21. Fear of mental health care and services

21.1. Could you kindly list what types of fear of mental health care and service, the BME users of the service have?

- Fear of being underestimated,
- Fear of being ethnic and misunderstood: Language barriers, lack of understanding & cultural awareness
- Stigma, being sanctioned, family finding out
- They have fear of wrong diagnosis and administration of wrong medication
- Institutionalisation fears, lack of sensitivity to MH issues and culture,

- Over-medication fears and side effects. Detention/Seclusion fears
- Ignorance is the main thing, Basic distrust of officialdom/Stigmatisation/racism
- Stigma, lack of cultural sensitivity, Eurocentric
- Having to publicly acknowledge personal/family situation
- Being perceived as mad, stigmatised by the community, not being understood by a practitioner from a modern family
- Stigmatisation of having a mental illness- feeling ashamed
- Not being able to access services
- Intrusion
- Fear of being committed
- Fear of being institutionalized and taken away from home. Also fear of others in the community finding out
- Fear of being judged, fear of being misunderstood. In some cases the clients have felt that mental health professionals would steer them away from religion.

21.2. Could you kindly list the basis of such Fears, according to your knowledge/experiences?

- Bullied by others, under-estimated by others
- Reality of not getting a job Cultural and MH difficulties are synonymous. MH professionals find it difficult to work with both and rely hereby upon a Western psychiatric model, of course.
- BME users are more quickly labelled with diagnosis and also some researchers indicate that they are more likely to be sectioned.
- Fear of becoming mentally ill, Eurocentric presentation of services
- Embarrassment at personal situation and feelings of isolation
- Not having medications, side effects properly explained, not having their fears properly addressed & dealt with. The feeling of shame is accurate as society in general does not understand mental illness
- By asking questions/Seeking help advice
- Shame
- Again due to lack of understanding of mental health and being in a state of denial
- Getting sectioned and detained in hospital
- Not being listened properly by the service providers
- Lack of knowledge of the mental health and myths/stereotypes told by family and community

21.3. Could you kindly suggest how these Fears could be reduced and by whom?

(a) Who can reduce such Fears?

- By Psychologist
- Society,
- NHS, doctors, mental health professional
- Government
- Staff, mental health trust, PCT's, Community organisations

- Better understanding of the clients' cultural background.
- Healthcare providers are the one to reduce fears
- Implementation of effective practises,
- Health care workers who knows about Asian lifestyle culture and religion
- Surgeries/ out-reach work by BME Health professionals
- Care staff, CPN, Social Worker
- Management/decision makers, practitioners, awareness in the community
- All professionals,
- Service providers
- Service providers
- Self, community centres, primary care services
- Increased awareness by education (including cultural sensitivity)
- Mental Health counsellors
- Family, family friends
- Mental health workers, counsellors
- Doctors
- Service providers through proper diagnosis
- Religious members, G.P, Ex-users, teachers in school educating the young generation

(b) How these Fears can be reduced

- By consulting, by reassurance
- Helping people gain control over symptoms & understand their meaning
- To stop misdiagnosis, stop giving wrong medication and false imprisonment to psychiatric patients
- Culturally competency training programs for all MH professionals,
- Respecting and being sensitive to ethnic and religious differences, help & assistance to service users by developing understanding & knowledge in mental health issues
- By providing information which is readable and welcoming. Mental health team liaising with local community
- More advocacy arrangement
- Putting them in an environment they are familiar with, also staff from their own ethnic background
- Further education can help, but in the long term, the emergence of ethnic minority specialists will be the answer
- Service providers and commissioners from BME communities who understand better
- 1:1 Session, counselling, family support
- 1:1 discussion in informal setting
- 1:1 with therapist and Counselling
- Talking, group work with other users and by mixing with others
- By giving good, accurate information, by supporting but not making patient feel belittled.
- By educating service users, professionals, all involved including family member, society in general
- Appropriate Medication
- Service provision through proper diagnosis

22. It is generally believed that there are disproportionately higher rates of admission to psychiatric inpatients units from BME communities

Table 59: Awareness of rate of admission

	No.
<i>I agree</i>	12
<i>Do not agree</i>	3
<i>Don't know</i>	15
Total	30

If you agree, could you kindly suggest how these admissions could be reduced?

- By Home Treatment Team (H.T.T) & Control and Restraint (CRT)
- People should be offered counselling and listened to: professionals need deep understanding of BME.
- More referrals from primary, community services, better assessment + assessment outcomes
- Better understanding of the dynamics of the family & individual
- By being more culturally and racially tolerant
- Family work outside in the community by skilled psychiatric counsellors
- More appropriate services in the community, awareness of MH
- Better care in community
- Getting them on light medication
- By educating the mental health staff, police force,

23. Why do you think some patients get violent?

- They don't get what they want
- Frustration. Same reasons as all of us. Not being understood
- People get violent because the way they are treated whilst in the hands of so called health professionals.
- Lack of staff understanding, understanding institutional covert racist practices, stigmatisation
- Poor understanding
- Depends on the person
- Misunderstood, not given adequate time to make decision
- Inability to express themselves in order to be understood
- A lack of understanding of what is happening to them, the feeling of not being in control - having no say, fear of what will happen
- Mental health issues, family pressure, unemployment, negative/insecure upbringing, drug/alcohol addiction
- Pattern of aggression in the family, not being understood or not having their needs met or medication side effect

- The medication is not correct dosage
- Being frustrated, over medicated and feeling helpless
- High levels of stress, pressure, frustration, fear which is internalised and then presents as violence. Not being able to take control of your actions
- Fear, misunderstood, not listened to, some are seen as aggressive
- Lack of medication
- Unable to communicate properly
- Inability to express their feelings - Self harm

24. How do such violent incidents could be controlled

- By Escalating or C&R (Control and Restraint)
- De-escalation
- Time out preferences, as compared to seclusion, control + restraint procedures, Involving multi-professionals rather than nurses, + psychiatrists
- Better understanding
- Only care and awareness of risks with minimisation of risks are possible.
- Effective restraint but more importantly by treating people with respect and understanding
- Having a dialogue
- Diffuse the situation, training of staff, how to handle such, and clients
- For client to have better insight into their care/illness - for them to feel that they do have a voice that will be listened to
- Accessing support such as anger management workshop, counselling, support group etc.
- 1:1 Counselling
- By controlling and keeping a balance of the medication and proper control of medication
- Offering opportunities to build insight and awareness as well as being able to identify and work through issues
- Have respect for person, don't treat them as hostile

25. It is generally believed that there are disproportionately higher rates of compulsory detention in inpatient units from BME communities.

Table 60: Awareness of compulsory detention

	No.
I agree	11
Do not agree	4
Don't know	15
Total	30

If you agree, could you kindly suggest how compulsory detention could be reduced...?

- By proper assessment
- By employing professionals who have a deep understanding and knowledge of how BME react when in distress as it's different from their white counterparts.
- More community involvement, as opposed to detention practices, better care planning procedures by MH professionals
- Early intervention, better understanding
- By practitioners becoming more culturally aware
- Better training of police and approved social workers
- Family needs, (more help with users at home)
- More cohesive/preventative/interventional/crisis care
- By diagnosing in the early stages

26. It is generally believed there are disproportionately higher rates of use of seclusion from BME communities

Table 61: Awareness of higher rates of seclusion

	No.
I agree	10
I don't agree	4
Don't know	16
Total	30

If you agree, could you kindly suggest how to reduce use of seclusion?

- By tackling the problem before it worsens
- More 1:1 sessions with clients, trained therapy staff on units, more activities
- Individuals that is BME and yellow white origins should be treated with the same respect
- Involving multi-disciplinary teams in care planning + treatment of inpatients.
- Understanding the problems, awareness of other cultures
- By raising awareness of mental health issues/illness in society

27. It is generally believed that there are proportionately more Deaths in mental health services following physical interventions with BME communities

Table 62: Awareness of rate of deaths among BME communities (N=30)

	No.
I agree	7
Do not agree	7
Don't know	16
Total	30

If you agree, could you kindly suggest how these deaths could be avoided?

- The police should just 'stop' using violence when dealing with BME group.
- Abolishing Control & Restraint (C+R) practices, better staff liaison with patients, again involving multi-skill agencies + professionals in care
- Awareness, training, fear, education
- By working with local authorities

28. If mental health patients are involved with the police, they end of in the prison:

Table 63: Views about Police involvement and imprisonment (N=30)

	No.
Yes	3
No	5
Not always	22
Total	30

29. If yes: how this could be avoided and reduce the numbers in prisons

- Better CJS + MH/Community services links introduction of link workers
- Training, Awareness
- There need to more places & more suitable places within the MH services for patients to be admitted
- Information, support, increase visits to home
- Should carry a card to state their status
- Should carry some kind of identification stating their status
- Education of people with cultural needs of individual

30. It is generally believed that BME mental health patients are given more drugs than other therapies

Table 64: View on level of medication (N=30)

Yes	14
No	2
I don't know	14
Total	30

If yes: why do you think it is?

- To calm and to bring under control quickly
- Assumption they will not benefit
- Because they want to get rid of BME patients
- Understanding racist practises by MH staff, lack of choice in treatment to BME, Eurocentric treatment procedures, failing therapies seen not appropriate for BME
- Lack of understanding of the cultural background
- Anti-depression, long term medication
- Prescribing drugs seems less time consuming and less costly compared to longer term intervention
- Easier, quicker, cheaper & often necessary
- Not enough care
- Not enough aftercare is given
- I believe that all patients despite their culture are given more drugs. There is a need for mental health professionals; including G.Ps to provide adequate assessment before prescribing medicine

And what other culturally appropriate services could be provided: Please list the range of treatments and therapies, which could help

- Going to church, temple, mosque, fulfil their religious needs
- Psychological therapies
- Multi agency assistance, faith workers, community engagement
- Culturally competent services
- Day hospital rehab facilities, dayouts and community programs
- Counsellor, Social worker from BME communities
- Counselling, talking therapies, family support, alongside complementary therapy - reflexology, massage
- Support group, day care to engage in activities and possibly one to one counselling
- Slowly ease them working them in the community & have responsibilities
- Cognitive Behaviour Therapy, Counselling, Psychotherapy.
- Including clients' religion in to the therapeutic orientation, using religion as coping skill towards progress.

31. It is believed that BME communities and BME service users can help in training the mental health staff

(a) Please say who in the communities can do such training

- Everybody involved in community development /advocacy/interpreters, carers
- Volunteers, social workers and other professionals' users
- Service Users
- Carers
- Personal experience of user

- Counsellors, Social workers, officers working in social issues in BME community
- Religious elders, homecare, those who run services such as social/lunch clubs, etc
- Day care services provider for BME including service users
- BME Service Providers
- Elders, Young people, teach about liking others from young age
- Those in authority churches, temples and mosques in co-operation with professionals in the field
- People who have experience with working with mental health patients
- Families of sufferer,
- Hospital - Care/Cure Plan Manager
- Ex-users, teachers, local leaders,

And how can this be done?

- Across agencies - Statutory and voluntary
- By way of conference & seminars, structured training programmes, workshops on cultural awareness using information videos and other material
- Commissioning appropriate training program
- Advertising in Asian magazines for volunteers to take up roles to support CPNs
- Awareness raising, specific training around religion sensitivities, culture
- Regular liaison with health workers
- Communication, providing activities to educate, opportunity for community members to volunteer with mental health

(b) Could you list what should be included in this training about the BME communities?

- Language, manner, how to deal in difficult situations
- Community elders & Church leaders as facilitators
- Cultural specific knowledge, skills to assess culture + MH difficulties
- Devising and designing courses, curriculum
- What are contributory factors to mental illness and how to avoid getting into it in the first place?
- Beware of religious factors
- Traditional practices,
- Generational gap
- Communication, community pressure
- Their experiences/feelings are vital and can play a huge role
- Cultural awareness & sensitivity, respecting ethnic differences unique within culture
- How to get the mental health patients to work & mix in the community
- Spending time with families, "on the job" training
- Knowledge of mental health, rights regarding mental health, how various agencies can be accessed

(c) Could you please say how the BME service users contribute to this training?

- About 30-40% in put in training programmes
- More involvement, across MH services, with leaders, commissioners, borough directors, frontline staff.
- By having a say
- Their experience of MH Services and how services can be improved
- Group workshops, interviews, open days
- Reviews, CPA meetings & evaluation forms
- Meetings and effective assessment of their need
- If they get back in to work, they can help others to get over their mental illness
- Explaining their experience of the mental health services and their views on how to improve the service.
- Communicating and sharing their experience with what had worked for them and what did not, what they learned

32. It is suggested that the BME services users should be involved/consulted in designing, developing and delivering the services. Could you kindly give your views how this could be done.

(a) Designing of services

- Restructure the services
- Sit on planning panels
- Actively involved in steering group committees
- Representation at commissioning level
- Client, Staff (Nurse, Psychologist, Dr.) input + training department
- Surveys, Postal questionnaires
- Consultation
- By assembling a panel - from different gender, ages, religious, cultures, etc
- Surveying service users on their experience
- Social workers, nurses
- Which service is required for that area, location, who should be m/h professional

(b) Developing of services

- Introduce new techniques
- Help staff think of needs
- Effective use of EOPs
- Local community events/ Attendance at religious venues
- Involvement
- By finding out their needs/experiences - good & bad
- Consultation meetings with Services users/carers
- People skills, language abilities
- Surveys
- Providing knowledge based on their own recovery, what did and did not work for them

(c) Delivering of services

- To be professional, diplomatic
- Advocates on training on unit
- Delivering outreach services to staff, involvement in services across sectors
- Primary care team meet with clinical team members of all levels + management to come up with package how things can be delivered.
- Engage in the monitoring process
- They play a role by being present during training explaining their experiences
- Deliver suggestions that have been put forward or requested by users
- All ethnic backgrounds.
- Surveys

33. If it is considered to recruit a workforce to deliver services for BME communities, what kind of professionals would you like to recommend being in that workforce.

Their Skills

- Should be very skilful
- Multi-skilled multi-lingual staff
- OT's, social workers, support workers etc.
- Those who have been inducted through appropriate recruitment procedures
- Knowledge about Asian background, and training, knowledge about services in community
- Listening/Negotiating
- Listening and Communication
- Endurance, Selflessness
- Understanding of BME religious, culture, and values systems and practices
- Good communication
- Good cultural awareness
- Non-judgemental, ability to learn and open mindedness
- Interpersonal skills, qualified
- To understand mental illness
- Experience in working with mental health services
- Effective communicators
- Interpersonal skills, counselling skills, experience working with various cultures,

Their personal qualities

- High quality
- Asian background, ability to talk in many languages
- Open/friendly/supportive/honest
- Patience understanding
- Approachability, professional, awareness to language, culture
- Empathic, approachable, professional with open mind

- Good listeners, open-minded, enthusiastic, empathy
- Non-judgemental, good communicator, Respect/understanding of culture
- Good communicator
- Patience, professionals
- Conducive to service user needs
- Communication, Listening skill, empathic
- Understanding
- Unbiased
- Genuine ambition, broadminded, open to challenge and ideas

Their backgrounds

- Mental health background
- BME staff trained in diversity, culture, cross-cultural, psychotherapeutically trained
- Including British born, who have strong Asian background
- Business & Profession
- Love and understanding of all types of people
- BME, open minded, willingness to learn
- People who understand and promote diversity
- Varied - not just professional, i.e., counsellors, therapists, nurses, etc. but those with other therapeutic skills, arts, music, horticulture
- BME
- Matching culture and religious background
- Multi-cultural
- Familiar with Asian background
- Any but have a keen interest in gaining knowledge about the Asian culture
- Not sure if background matters
- Cultural understanding

3.4. Qualitative Findings

3.4.1. Introduction

As pointed out in methods section, a number of methods were used to collect data both qualitative and quantities. There were a number of sources of qualitative data collection e.g. Focus groups meetings, one to one conversations and interviews and consultation with various stakeholders at a half day seminar attended by 50 people.

In this section the themes which emerged during these deliberations are presented.

3.4.2. Focus groups and one to one discussions

Since there were five mental health service users in the research team it was decided from the onset that any discussion within the team would be documented and that special

sessions will be held with the service user members of the team as focus group discussions.

Therefore the information presented in this section is based primarily on those debates and discussions that took place during the team meetings and the focused discussions.

The tape recorder was routinely used to capture the details during these conversations.

The transcription of the recorded discussions was analysed and hereunder presented under five broad themes.

(1) “I am not listened to”:

It is believed by some that *“I see my voice is silent whenever I go to see the people who have the power in terms of mental health issues”*, said one of the participant. For example one of the users said that *“I would like to be referred to a particular Day Care Centre, which I believe is suitable for my needs: I have been pleading with my psychiatrist, to refer me to that Centre, but they think they know best”*. *“I do not have the power to choose the treatment I need, let alone getting involved in designing one for myself”*.

She added that she wanted to get involved in designing the services that she thought were best for her or appropriate for her. *“The irony is that the psychiatrists, who refer people to certain centre, do not know these services and centres. They have never been to these places”*, she concluded.

There was general consensus that *“Involve us, engage us in developing the services, and if we have to deliver then let us do it, provided we are adequately resourced”*, stated by a number of participants.

(2) Being Asian with deep-rooted values and belief system, based on religions and cultures – between two cultures and/or healthy biculturalism

Deep-rooted cultural characteristics

It was generally held view that with regard to the values and beliefs system of Asian communities, professional can hardly scratch the surface, it is difficult to reach the deep rooted value systems and their experiences. The Asian communities generally and the users in particular find it difficult to express those inner feelings. They also realise even if these values and beliefs are cause for concern, these are not up for questioning. There is a need for specialist facilitation, which Eurocentric professionals or those trained in Eurocentric tradition cannot reach.

The challenge is to get to ‘under the skin’ information and hope that the information is not used against the community, by way of stereotyping them further. It was believed by one of the participant that if the white institutions realise that there are certain values,

customs and beliefs which are exacerbating the situations and conditions then there would be more efforts to anglicise the communities and reject their background and ethnicity, which in turn will create more stress and would be detrimental to mental health.

Socialisation and Taboos

With regard to ethnicisation or socialisation within the Asian cultures and ethos, it was suggested by one respondent. *“The psyche has not changed or moved, it has been transplanted into a foreign place”*.

“I feel for me -- everything I do is affected by the way I am or the way I have been brought up or where I come from. It is this socialisation that tells me what I read, how I read, how I respect my older”, for instance.

It was also asserted, *“The Western mind just cannot understand how much we destroy ourselves in the attempt to maintain our cultural and community wholeness”*.

It was also admitted, *“At some level there is denial, and we need to get to the root of denial – why people deny or censor some information, why certain issues are such a taboo”*.

“Unless we deal with this denial or break the taboos, the Asian communities with mental ill health would not be able to access the appropriate services, nor will the professionals and the institutions be able to provide responsive services”, it was added.

Poverty and economics was also considered an important factor e.g. *“sending money back home creates poverty here”*, *“but we cannot openly talk about – both husbands and wives have loyalties to folks back home”*.

It was explained by one of the respondents, that *“we inherit our moral values from our parents through our upbringing in our home environment”* and *“the interplay with the external Western world creates Western Asian persona”*.

Living in time capsule

With regard to lack of integration of the first generation and generational gap, the following five statements were made by various contributors.

(i) *“Seniors in our community are first generation immigrants and they operate from their standpoint relating to back in the sub continent. There is a large number who do that, because they have not ‘gelled’ with the communities in Britain, so therefore the interface of that generation with the younger generation, is bound to create major conflict – it is not just generation gap it is major cultural shift”*.

(ii) *“People over there (back home) are relaxed about how things are done, which is ‘home’, over here there is struggle to hold on to that which is very dear, our culture”*.

(iii) *“We miss the usefulness of having arrived in a different place – we still socialise in the same communities”, and there are valid reasons for that.*

(iv) *“There are those who have been able to get out of this vicious circle and there are those who are ‘trapped’ - may be due to poverty and are forced to live “parallel lives”.*

(v) Regarding the issue of ‘white flights i.e. when white communities and families moved out of those areas, where Asians and ethnic minorities started settling in on arrival after the second world war, it was added that *“even the well to do South Asian themselves have moved away from those illiterate communities and have literally abandoned them, which has not helped their lot”.*

Home Environment and values

Socialisation into Asians values, practices and beliefs systems is distinct experience and similarly immigration related issues, and their minority status Asian are also specific concerns that impact Asian communities.

These community experiences engender conformity to family and community norms. However one of the participant questioned that *“If it is good thing to be what we are and remain so, as Asians, as Muslims, for example, then why mental stress”?*

Fear of community judgement

*“Certain values we hold so dearly for centuries now, which suddenly have become cause for our mental health. It might have caused mental health problem but we do not have evidence. **Log kiya kahain ghey** has been a malaise in some ways and in other it allows to prevent us from falling than we might”, one participant suggested, and added, “on the other hand ‘**Log kiya kahain ghey**’ is total fear of exclusion from the community, rejection by the west and the host community”.*

“Respecting elderly and obedience without question, is considered a very good value but in the western culture people think there is something wrong with you and your values are being questioned, creating doubts”, said another participant.

“Our values are being questioned and that is creating stress and mental health problems”. “Therefore the government is interested to accommodate these values in the service delivery that undoubtedly will be effective” was observed by one contributor. .

The same participant continued, *“The question of obedience and compliance is common in all the functional families – and any thing associated with dysfunctional would be rebellion, non compliance, and disobedience –Within that functional dimension there are certain values which are in conflict with the culture we have chosen to live.*

“Back in sub continent these were not questioned “Log kia kahain ghey” was taken on board all the time and there were built in safeguard against that for conforming and no

choice”. *“The fear of community judgement is there as well prevents you from doing something,”* she concluded.

She added, *“One big difference is that our community tends to be community based and increasing our host culture is individual based. Where individual is valued and reaps dividends”*.

Matrimonial challenges

In the Asian cultures, it is a challenge to keep the marriage, *“damn the children damn the rest of the world, the marriage must work, it is a cultural aspect”*, added one participant. She further said, *“If divorce is a solution then so be it, but sadly due to value and belief system that divorce is another taboo subject. More stress is added after the divorce and psychologically problems are created”*.

“The concept of divorce does not exist in our family”, said one of the participants, *“I am the first divorcee in both my husband and my family. According to Hindu way of thinking the marriage is a life long partnership. There is stigma attached to the divorce for women especially,”* she added.

Regarding perceived disproportionate impact on women, it was generally believed that: *“Whenever there is breakdown of relationship between man and woman, it is always the women, who are troubled by the problems than men. I am not sure whether it is common in every culture”*? She questioned and added, *“It is always worse for the women, she suffers the most. The man has a much powerful role in the family as patriarchal – has an easy way... Women are less powerful”*.

External environment

There are a number of aspect which external to home environment, discussed above, which have both negative and positive impact on the individual e.g. education, workplace, financial aspect and so forth.

Education: It was generally felt and endorsed emphatically by a teacher in the team, that *“different treatments that teachers give to children at school e.g. White children get better or different treatments. She also added, “On occasions, due to unfavourable treatment in the society at large, children get scared at early age and it stays with them for the rest of the life”*.

Work place: *“discrimination at work place, or mal treatment or institutional racisms, causes stress”*.

Financial aspects and *“level of poverty within certain communities does make a difference, which determines the kind of social environment one lives in and gets influenced and affected by it”*

Poor housing does affect mental health – facilities, environments deprivation –

Between two cultures aspects. It was generally believed that if healthy biculturalism does not develop due to excessive polarisation or lack of balance between Anglicisation and ethnisation, then the pressure mounts. *“On one hand there is fear of losing culture and getting away from one’s religion, community and parents values, and on the other temptation to be free and non compliance. These environments engender conflict within individual, leading to stresses and mental ill health”.*

Similarly *“not to have white friends: social mixing and networking prevented for the fear of being anglicised – it is likely to affect mental health at a later stage – not allowed to socialise and befriend other people”.* Whereas *“peer group pressure, leading to, for instance, drug user crime, and other social ills, equally influence adversely”.*

Immigration related stress is also included in the external environments e.g. drop in personal socio-economic status following migration; inability to speak the language of the host country; separation from family; lack of friendly reception by surrounding host population; isolation from persons of similar cultural background; traumatic experience or prolonged stress prior to migration; and adolescent or senior age at time of migration.

(3) Perception of mental illness

Their perception of mental health or mental ill health was explored by asking, what they thought mental illness was and so forth.

Cultural and religious dimension

“Initially mental health or ill health is seen as madness”, said one of them, *“and usually efforts are made on behalf of the family to find out whether they were possessed”.*

It was believed that *“There are different aspects in religion and spiritually that at time do not help e.g. Belief in the Will of God or concept of Reincarnation”* Therefore this belief system encourages ‘lying down model’, i.e. *“There is nothing you can do about your conditions: accept it as a fate”.*

However philosophically it was indicated, *“We then come back to the maturity of our own spiritual journey, which dictates whether we should find solution or leave it to God”* and *“It is not just prayers five times a day”.*

However one of participant resented the fact that *“When you have mental health problem, free will goes out of the door”* *“It is not your spiritual development when your family decide that you got to go to Maulvi (priest) – you do not matter”.* Generally it is the families who find it difficult to cope. *“What would be most supportive is to have their support and love and that would be the priceless and that would go three quarter of the way”.* *But sadly they lack understanding, based on their cultural and community beliefs.*

“The blame is on the person who is experiencing ill mental health. “It is you who are – you have brought it on your self” On the other hand *“people with mental health*

problems blame the world, they are not able see what is inside causing the problem - what causes mental health problem are some times internal to us, that internal bit is created by our upbringing, our experiences and general values and beliefs systems”.

Nonetheless it is not advisable to conclude that “*our ‘Asianess’ causes the problem”*. “*No it might make it worse but it is not the cause of it – it happens in any country – it become worse if you are not in your own country”*”, emphasised one of the contributors. She added that “**Pagal hona** (to be mad) is not considered very fashionable even in your own county”.

There are a number of factors that cause stress and strain, particularly in new environment e.g.

- Underachievement or fear of it
- *Log kya kahain gey*– (What would the people say?) community judgement
- The Strength of the patriarchal society and it influences
- Conforming to the community values and norms
- The position of the male in our society and similarly
- The position of female in the family, community, and society.

Definitely there is a ‘**Asian psyche**’ -the personality development that interplays with certain factors that makes us prone to certain conditions and leads to collapse and there is the psyche of male and female psyche with distinct cultural context.

(4) Cultural competence and fear of victimisation

There are cultural needs and there are mental health needs, and the interplay between the culture and mental health needs, which is very significant but “*It is not immediately understood”*”.

“If we present our selves with mental health problem – they just go for the conventional checklist and diagnose and label without even trying to look at the cause which at time are not even given to them by the family or the patient because of a variety of reasons to do with cultural, value and belief systems”. There is always the fear that “*If we give this information to professionals, how would they be able to treat better or diffidently and not use the information against us, because of stereotyping, prejudice and racism”*. “*The Eurocentric strategies are not much help”*”.

Therefore it was suggested that as a starting point to providing responsive services it would be beneficial for all concerns to define:

- What are characteristics of Eurocentric mental health service?
- What are characteristics of semi-Eurocentric mental health service?
- What are characteristics of BME centric mental services?
- What are the characteristics of Asian mental services?

In this context it was also observed *“BME staff are running the white set institutions”* Therefore, *“getting more black people is not the solutions if they continue to run the white systems with white norms and white mind set”*.

It was observed by one of the user of a Day Care service *“If the place is funded for a small number of people, how come there are four to five times people using the service”*. *“The reason is simple that these kinds of services are needed and if have that many here, how many more would be there that we are not reaching or that they are not aware”*.

With regard to understating and taking into account the cultural background of the Asian communities, one participant observed that *“One thing could be brought to their (Professionals’) attention is that a great deal of emphasis is put on community values, family values, so if a break down has occurred of any kind then it should be appreciated that it has come about after working extremely hard on those value system and there is such a disparity that the entire thing has collapsed”*.

The question of Trust

“At time you do not tell them that you are suicidal, the minute you say that you are off to Stone Leigh”. *“I know that institutionalisation is not the place for me”* I know my needs; they can only offer a cocktail of drugs, whereas I need proper engagement and support yet despite my ability to articulate, I find myself silent”, observed one of the participants.

Linked with 9/11, it was pointed out by one of the participant, that *“people do blame Muslim and I being a Muslim suddenly started believing that perhaps I was part of that ‘terrorist’ group”*, He added, *“obviously I could not trust people with my feelings, fearing I could be reported to the police”* *“Did the system help”*, he questioned, *“because I was not telling the real reasons for my distress”*. Users do not trust the system so they do not tell and share certain type of information.

Treatment and day care and rehabilitation

“There is much more emphasis on medication and institutionalisation -much more than the white and I know it is common with black”, said one of the participants, *“Asians in mental health institutions stay in for longer: there is no understanding they are lock up for nothing”*, she added.

It was observed, *“Although on face of it there are mental symptoms but underlying there are other issues which are cultural specific which are not understood to explore. There is no checklist and norms against which to assess their peculiar behaviour”*.

“One situation”, a participant explained, *“I can remember being extremely low – they have 11 point checklist these health professional at the acute end and I was ticked off and they invited me to say in – I said no way - I have a child and I have to go home”*. *“We will have to section you”*, they threatened. *“It took me best part of two hours to convince what was good for me under the circumstance, I was able to do this cas I was articulate enough”*, she concluded.

“Being among people who are seriously ill, makes the circumstance worse. Services do not understand”, observed another participant. *“What would work is a degree of support”,* *“what you get is, that, we know what is good for you”,* he added.

During the discussion it emerged that *“Some times there are mental health problems because some time there is no harmony between the internal and external environments, which causes conflict – conflicting situation or polarisation”*.

It was also explained by a couple of participants that *“We first try support system within the family and that does not work then try and get professional help”,* in which case it has to be a pretty serious situation, if professional help is sought. Qualifying the need to get professional support, it was explained that, *“An individual does not chose to be helpless”* *“you have to be in a pretty serious position, especially if your family is in denial – denial aspect could be very damaging”* (the home environment). *“If I had to shout it has gone beyond the realm of speaking softly” and if they expect you to speak softly to provide help – then there is no help”*. At times you feel that *“you do not have even the language skill to explain to you that you do not even make sense”*, said one of them.

Alternative remedies – spiritual aspect

There is such thing as the Islamic counselling – spiritual aspect – *“My own understanding is that whatever the community, Hindu, Muslims, Sikh, we stick to our own kind that gives the security”,* it was observed.

(5) Targeted vs. mainstreaming

There is need to address these issues of dedicated and targeted services and the mainstream services, but it was felt that it was not that straightforward. Following are some of the issues emerged generally endorsed by all the participants.

(i). One solution could be that the services should be designed, developed, and delivered by the people themselves – they should be empowered, skilled to deliver. Those who have the ethos of the community and understand well. They should deliver services for their own communities, it was generally observed.

(ii). If we assume that the mainstream will never be able to deliver culturally competent services, we fear that the marginalised services if not properly resourced will work against the communities they will lose out They will have to settle for crumbs.

Unless you are institutionalised say in Stone Leigh you will never be able to access those services.

(iii). It is important to understand that mainstream institutions cannot fully be culturally competent, because they have to work for and with various cultures – there always would be the gap – if it is overdone to say cater for the needs of Asians or African Caribbean then the Whites will suffer and vice versa.

(iv). And it is not possible to exclusively set up institutions for cater for the needs of BME communities – resources will not allow it. Small scale targeted and dedicated services can be run like the Qalb but not Stone Leigh or Thorp Combs etc. “Involve us engage us in developing the service and if we have to deliver then let us do it provided we are adequately resourced.”

3.4.3. Key points raised at the half day seminar

Introduction and key points as themes

The half day seminar was held with twin objectives: firstly to contribute to the local DRE Steering Committee’s action plan of promoting *DRE* locally and launch the community engagement research project, to enlist support and secondly to chapter a variety of perspectives regarding mental health of BME communities generally and of the south Asians in particular.

Twelve different speakers representing a cross section of local and national perspectives, both voluntary and statutory contributed to the seminar (Please the Appendix for the programme and list of speakers). The speakers included two service users, who were members of the research team. Around 50 delegates from various local and national agencies attended and contributed to the deliberations.

A full 44-page report of the seminar, comprising summary of the twelve contributions, bullet key points, and documentation of questions and answers session is available from the Qalb Centre. Hereunder the synthesis of the key points is presented under six themes.

(i) Recognition/realisation to take action

The Race Equality lead from the London Development Centre emphasised that there is recognition of the need to Deliver Race Equality in Mental Health Care, within the National Health Service (NHS) and the government’s decision to have focus schemes to tackle and address race equality in Britain indicates that too.

The key mental health worker and the DRE steering committee lead explained that the PCT is addressing the three building blocks. She added that the Steering Committee will develop and oversee the work programme of Community Development Officer(s) and that the steering committee is serving reference group for the Qalb Community Engagement Project, too.

However the Vice Chair of the PCT suggested that the commissioning role of the PCT is rather weak, which needs strengthening so that patients get more choices including services from the private sector. He added that the fitness for purposes review will ensure that the PCTs are fit for the new purpose i.e. as commissioners rather than as development agency for primary care, which will open doors for BME providers as well. Therefore BEMs need to build the skills required to get the institutions to recognise their needs and the need for change. He further added that Waltham Forest PCT was running a £14M deficit budget, which makes it extremely difficult to develop new services.

(ii) Key drivers

The Race Equality Lead from the London Development Centre explained that the key national driver for affecting change was the Race Relations (amendment) Act 2000 and production of Race Equality Scheme i.e. an Action Plan. She also highlighted the general duties of the Act as:

“Public authorities shall, in carrying out their functions, have due regard to the need to:

- eliminate unlawful discrimination;
- promote equality of opportunity;
- Promote good race relations.”

Besides the Race Relations (amendment) Act, 2000, she described the following anti-discrimination legislations as well, which were equally applicable.

- Human Rights Act 1998
- Disability Discrimination Act 1995: Final Phase of Part III –October 2004
- European Directives – Race, Religion or Belief, Sexuality and Age

In addition to the above mentioned anti-discrimination legislations, the following specific national drivers were also mentioned:

▪ Delivering Race Equality [October 2003]

Sets out minimum standards for those involved in planning, delivering, and monitoring local mental health services in order to meet the needs of black service users and their carers. The standards are based on clear evidence of the levels of inequality experienced by these communities

▪ Inside / Outside [March 2003]

This report sets out three key objectives and recommendations for change to improve the overall mental health of black and minority ethnic people living in England:

- To reduce and eliminate ethnic inequalities in mental health service experience and outcome;
- To develop the cultural capability of mental health services;
- To engage the community and build capacity through community development workers.

▪ Breaking the Circles of Fear

Describes the barriers experienced by African - Caribbean men and their families when accessing mental health services and the coercive forms of treatment that they tend to be subjected to.

▪ **David Bennett Inquiry**

The Inquiry into the death of David Bennett and sets out 22 recommendations for the improvement of mental health services as experienced by black and minority ethnic communities.

(iii) Consultation, involvement, community engagement

The Director of TAHA, a national voluntary sector health agency, believed that the consultation with BMEs was tokenistic and that the BME communities should negotiate change and should not participate in tokenistic consultations.

Whereas the University support worker spelled out the key ingredients of community engagement model, which the University of Central Lancashire has perfected over the years.

The Community Development Worker designate said that her role would be to facilitate communication to overcome language barriers, empower BME communities and build their capacity in order to improve access to facilities, ensure equitable resources allocation and also give advice to services providers to impacting policy development and training of staff.

The community engagement research coordinator emphasised the need for engaging with a cross section of stakeholders and advocated the research focus to captures experiences of BME communities regarding extent of racism and level of discrimination.

He said that the project would deploy multiple methodologies to access information from a variety of stakeholders and in depth analyses would be carried out to gain insight into Asian values and beliefs systems that has bearing on mental health conditions and that the analyses would compare and contrast home and external environments which facilitate recovery or exacerbate the mental health conditions.

He highlighted the rules of engagement to sustain contacts with all the stakeholders with commitments and convictions.

(iv) Responsive services

Both the service user researchers said that the BME communities usually complain that they do not receive appropriate services responsive to their cultural needs and that they are often stereotyped and sent to high security hospitals and prisons.

They explained that there were many deep rooted issues that many Asian people with mental conditions cannot share, relating to their families, communities, and their peculiar experiences in Britain. Therefore there is a need to gain confidence of each other – professionals and users of services. Service users to be engaged in designing, developing and delivering the services that they think are appropriate to their needs.

The also suggested that there was a need for providing extensive information to service users for them to make decisions regarding what was best for them and emphasised the need for improved culturally sensitive services for Asian communities.

(v) Resources – allocation-utilisation

A number of speakers made different points with regard to lack of resources, allocation of resources to redress the imbalance and appropriate use of additional and targeted resources. It was pointed out that at times resources allocated for BME communities to redress the imbalance and provide appropriate services were not used by the local public sectors for the purpose these resources were allocated e.g. recently allocated funds to appoint community development workers to engage with the communities to deliver Race Equality in Mental Health Care were not were deployed.

It was also argued that in certain geographical areas, the BME communities are in majority and they are no longer minorities, but the resources allocation and services provision are not equitable.

The Race Equality Lead explained that the Government allocation of additional funding for this programme included around £21 Million to appoint 500 Community development workers and carry out other related work. Unfortunately in the country and in London most PCTs failed to use the funds allocated for this purpose. It has serious implications for the Delivery of Race Equality in Mental Health Care.

However the contribution made by the Associate Director of PCT highlighted the additional resource for capital volunteering and befriending in the Borough would compliment the DRE Action Plan by empowering communities and voluntary sector to deliver the programme.

(vi) Racism and discrimination

The Director of TAHA said that acceptance of ‘institutional racism’ by the public sector and the institutions had become almost ‘fashionable’ and the mindset of the ‘white-run’ institutions which generally influences and shapes the services delivery.

He added that the mental ill health conditions of the BME communities were made worse because of their experiences of racism, discrimination, exclusion, Islamophobia coupled with the social deprivation in the areas where they live and many other disadvantages experienced by them e.g. high unemployment, poor education, poor housing, poverty, and low income. Therefore he suggested that perception and experiences of racism and discrimination needed to be addressed seriously.

4. DISCUSSION

Aim of the Community Engagement Project

The aim of the project was to explore the availability of mental health services for South Asian communities in Waltham Forest, and ascertain views of both the service users and the professionals on their appropriateness with regard to faiths, cultures, and diversity generally, and suggest how they could be improved.

Besides attempting to achieve various objectives, (See Section 1.8.) it was envisaged to empower and facilitate mental health service users and their carers (as workers/researchers and volunteers) in engaging with mental health service providers to voice their needs for shaping the mental health services provided for them. To this end a number of mental health services users and key workers were engaged as researchers, who participated in various platforms to air their views and were successful in engaging with the wider 'user community'.

In discussing the findings and other aspects, the following eight themes have been chosen.

(1) DRE awareness:

Prior to *DRE* a substantial body of evidence had been gathered by the *DoH* and various sources. A number of legal drivers also necessitated the production of Five year plan to address the issues and concerns around mental ill health of BME generally and within that variety of other minority communities e.g. African-Caribbeans, South Asians, Refugees and Asylum Seeking communities and new arrivals e.g. Eastern European economic migrants. The Government has allocated reasonable funds for the implementation of key elements e.g. approximately £16M provided to the Primary Care Trusts to appoint 500 community development workers, besides other initiatives.

If general body of professionals are not engaged and informed about the floor targets, the Delivery of Race Equality in Mental Health care at face work level would not be satisfactory. During the past 14 months or so the North East London Cluster Group met only twice and Waltham Forest DRE Steering Committee, although pursuing the agenda with the help of a dedicated worker, has not met regularly at six weekly intervals as planned. They are still at information gathering stage. The information gathered, is not robustly monitored, to take any corrective actions.

2010 visions would only become reality if all the stakeholders, including face workers are fully engaged in delivering the programme and achieving targets.

(2) Research Findings

The cliché comments about the cultural competent services provision were all too common i.e. provision of halal food, prayer corner, Asian staff and interpretation. However there was candid admission by some professionals that "*Cultural and Mental*

Health difficulties are synonymous. Mental Health professionals find it difficult to work with both and rely hereby upon a Western psychiatric model, of course”.

It was generally believed that with regard to the values and beliefs system of Asian communities, professional can hardly scratch the surface. It is difficult to reach the centuries old deep-rooted value systems and their current experiences, too. The Asian communities generally and the users in particular find it difficult to express those inner feelings or equally difficult for professionals to explore these aspects in depth. They also realise even if these values and beliefs are cause for concern, these are not up for questioning. There is a need for specialist facilitation, which Eurocentric professionals or those trained in Eurocentric tradition cannot reach.

When discussing violent behaviour and detention, it was stated that there was a need to employ “professionals (regardless of ethnicity) who have a deep understanding and knowledge of how BME react when in distress as it’s different from their white counterparts”. This ‘distress’ has to be examined in the context of their day to day experiences in British society, for which deeper understanding, empathy and special skills are required. It was also considered appropriate to “Understanding racist practises by Mental Health staff, lack of choice in treatment to BME, Eurocentric treatment procedures, and failing therapies seen not appropriate for BME”.

The challenge is to get to ‘under the skin’ information and hope that the information is not used against the community, by way of stereotyping them further. It was believed by one of the participant that if the white institutions realise that there are certain values, customs and beliefs which are exacerbating the situations and conditions then there would be more efforts to anglicise the communities and reject their background and ethnicity, which in turn will create more stress and would be detrimental to their mental health.

The personal experiences of South Asian mental health service users within the mental health institutions varied. Those who could speak English language and were provided halal food, prayer corner and were allowed to wear scarf, were generally satisfied with the so-called cultural competency of the service. However both the professionals. who completed questionnaires and those users who contributed to the focus group debates felt strongly that the deep-rooted value and belief systems were much more significant in understanding to treat properly. When asked, the users were found reluctance to share intimate and home-, culture-, religious-specific details with professionals and on the other hand professionals also felt that it was difficult at times to probe to get relevant details which could help in care pathways.

Whereas there are still those professionals who believe that “*The mental health system should not be specific to any certain culture but to have a normal standard of values of this country*”, - a very assimilationist view: and a colour blind view expressed by

another professional saying, “*All clients are treated the same and given the same support and service*”, moreover “*I think services providers are meeting needs otherwise users will not use NELMHT*”. These kinds of comments do not take into account the appropriateness of the services, level of satisfaction with the services and under use and lack of access to the services.

There was a view that prescribing drugs seems less costly compared to longer term intervention, particularly when you are sure what to do any way. Therefore it was considered important to understand racist practice by the staff hence lack of choice in treatment. There is need for proper assessments before providing drugs, choice for therapies and different treatments.

(3) Fear of Stigmatisation (Reluctant to share personal information)

Notwithstanding the deep-rooted belief systems and values referred to above, there are, no doubt, a number of issues and concerns, as explored in the Five-Environments Analyses (FEA), which some professionals also felt that despite trying hard, “it’s very hard to get the true story out of them”. This could be due to a number of factors, e.g. “due to their being treated as outcast within the community” or “fear of members of extended families being informed of details”, or “too shy and shamed to discuss issues”, and “feeling embarrassed and facing difficulties in explaining personal and sensitive issues with others”, which is based on their upbringing, cultural backgrounds, non-integration and lack of understanding of mental health professionals and lack of trust in them.

Among various strategies it was felt by most respondents, both users and professionals that there was need for general education and awareness among the Asian communities in order to combating guilt, stigma, and shame and empowering communities and supporting families and friends, including spiritual support. The families has important role to support and care for the mental health services user, but unfortunately the families themselves are unsupported, in terms of knowledge, awareness and where to seek help from.

(4) Personal and Team Development

Different research team members had different skills and competencies and all of them had the opportunity to contribute at various programmes, which in turn assisted in their personal development of skills, confidence and created opportunities for further involvement. They organised meetings and seminars, they participated as speakers at local, national and international conferences, attended DRE Steering Committee and Community Engagement Network meetings and being involved by NELMHT in users’ involvement and training programmes. There was a great deal of team spirit to support each other in completing their assignments for University qualification, and they received good grades e.g. one distinction, and three merits.

(5) Methodology and design

There were enormous learning opportunities for the research team to put into practice what they had learnt in the class room. Eight draft of the users' questionnaire were considered by the team each time picking up issues to do with for instance wording of the questions and use of simple language to control ambiguity; giving clear instructions to participants what needed doing; presenting questions and section in logical order and avoiding leading questions and keeping the focus sharp to getting the requisite information. The questionnaire was neatly divided into sub sections so that the analyses and presentation of data became easier.

Researcher did take copious notes if the respondents were not able to complete the questionnaires themselves, but on a number of occasions space had to be created to deal with emotional issues raised by the respondents, which impacted the researchers as well. Research team were fully prepared and trained to consider any ethical issues and deal with unexpected situations.

Similarly four drafts of the professional questionnaire were considered

(6) Appointment of Asian Staff

Both the professionals and the mental health services users stressed the need for the appointment of Asian staff. Mere presence of black and brown faces would not deal with the complex issues in question adequately, unless the job descriptions and personal specifications of certain staff are reviewed to incorporate specific tasks to be performed by the staff, regardless of their ethnicity.

They should have specific skills to be competent to address spiritual needs of diverse faith communities or communication needs of linguistic minorities. They should know the specific circumstances that contribute to mental ill health of Asians and equally be willing and equipped to consider unconventional and alternative strategies.

Any staff trained in Eurocentric traditions, including Asians, African Caribbeans or any other BME origin, would not necessarily have the skills or the knowledge for 'Transcultural orientated' mental health work, unless they are re-trained.

Moreover it is essential to reward such qualified staff appropriately as well. If their linguistic skills are required then this should be reflected in their evaluation/remuneration

(7) Perception gap: 'singing from the same hymn sheet'

There seems to be general consensus for '**doing different things; and doing things differently**', among the professionals, users, carers and volunteers, in terms of policy and practice and expectations, but there is disparity and gap, between 'need analysis/ needs recognition' and 'meeting those needs'.

However both at individual and institutional levels there is evidence to suggest that phrases like these are too common: “cannot do; cannot afford to do; do not have the skills to do”, ‘doing our best within the resources’, ‘it is not cost effective’, ‘we treat everyone the same’, ‘do not see the need to do anything different’, ‘their religions and cultures are their private matters’, as one of the psychiatrist said to a Muslim female patient, “I am an atheist, I do not know anything about religions”.

There is a ‘problem-oriented’ debate that takes place all the time within the diversity context, that “the Asians have language problems, they have religious problems, they have cultural problems”, and so forth. As one of the professional said, ***“Cultural and Mental Health difficulties are synonymous. Mental Health professionals find it difficult to work with both and rely hereby upon a Western psychiatric model, of course”***.

(8) Mainstreaming and targeted work

There is no doubt that ‘mainstreaming’ services for ethnic minorities and other excluded and marginalised communities is the ultimate goal of most services providers. It is cost effective and politically accepted as integrated services provision. But it is not always possible, therefore the case for targeted services for BME communities generally and South Asians particularly will always be there, due to diverse languages, cultures and religions.

Notwithstanding the efforts of many public sectors institutions who have given serious consideration to addressing racial discrimination, sadly the historical failure of welfare services generally to meet the needs of BME communities still lingers on. It is the task of all the public sector agencies to ensure that all traces of this failure are extinguished once and for all.

The philosophy and the policy to develop and provide a comprehensive and fully integrated range of services for all the residents must nevertheless recognise the need for special and separate services provision for all those who are at risk for being excluded.

These special, separate, targeted and dedicated services such as the Qalb Day Care or the Black Peoples’ Mental Health need recognition and support. These are essentially the mainstream services provision in a Borough like Waltham Forest for the BME communities. There should be parity of resources allocation. It was found out during data collection, that certain ‘mainstream projects’, which have established say ‘Asian mens’ groups’ or ‘Asian womens’s group’ are now disbanding these initiatives and encouraging Asian services users to use the services at the Qalb Day Care, without resourcing the Qalb adequately.

5. CONCLUSIONS AND RECOMMENDATIONS

5.1. Conclusions

The following sources of evidence were used to draw conclusions and make recommendations:

Seminar/launch report, focus groups, one to one, conferences, literature review (inc. findings of 11 pilot projects), questionnaires, deliberations at DRE steering committee and Cluster Group meetings, Community Engaging Network meetings – weekly team meetings and fortnightly meetings with support workers.

5.1.1. Personal experiences

The personal experiences of South Asian mental health service users within the mental health institutions varied. Those who could speak English language and were provided halal food, prayer corner and were allowed to wear scarf, were generally satisfied with the so-called cultural competency of the service. There are still assimilationist and ‘colour blind’ views among some professionals about the service delivery.

5.1.2. DRE Awareness

There is evidence to suggest that nationally and locally in Focused Implementation Sites the agenda is vigorously pursued, at least at policy level. Generally there is lack of awareness among the mental health professionals, particularly among those who completed the questionnaire.

5.1.3. Differential and discriminatory conduct

Some participants did express the concerns about adverse differential conduct and behaviour at inpatients stage, in Rehab and Day Care at the hands of staff, but were reluctant to report due to embarrassment and stigmatisation.

5.1.4. Appreciation for cultural sensitivity

Those ‘mainstream’ Day Care Centres that provide some culturally sensitive services albeit superficial were appreciated by the users. The users would very much wish to attend those centres, because they are well resourced and equipped with a wide range of activities, compared with the dedicated service such as the Qalb Centre, which is not well resourced. Sadly they are not given access to those facilities: not referred by the psychiatrists.

5.1.5. Satisfaction with cultural responsiveness

The service users who exclusively use the Qalb Day Care Centre, because of cultural, linguistic and religious needs were well satisfied and recommended for similar facilities in different part of the Borough. However some professionals perceived the Centre as a

Muslim Centre only. It is pertinent to mention here that there is significant number of Muslim community of Pakistani origin in the Borough, who experience higher rate of mental ill health and also live in the immediate neighbourhood of the Qalb Centre. It is equally relevant to note that they receive referrals from various institutions, therefore whoever is referred to them they will cater for.

5.1.6. Significance of faith and spirituality

Issues around faiths and spirituality were considered very important both by the users and the professionals but both felt that it was not possible to consider deep-rooted religious and belief systems. These belief systems have serious implications during diagnosis, care plan and treatment.

5.1.7. Differential patterns of mental illnesses

There was general recognition of the differential patterns of mental illnesses among various BME communities i.e. Asians, African-Caribbeans and Refugees and Asylum Seekers and some of these conditions had their roots in their specific environments.

The strong endorsement by the professionals for the Five-Environmental Analyses suggests that their specific upbringing, conforming to community and family expectations, between two cultures, religious values and practices, workplace and schooling experiences, housing conditions, racism, discrimination and harassment, identify confusion and lack of self esteem, among others, do contribute to their mental ill health.

Similarly there are certain 'community specific' mechanisms and strategies that tend to alleviate the conditions as well e.g. trusting relationships, religions, community support, cultural practices, culturally competent staff/nurses, family support, MH promotion, dealing with language barriers, sensitivity to Asian culture, recognition of faith, incorporating faith/culture in treatment, understanding cultural identity, family closeness, employment, financial resourcefulness and lack of domestic violence.

5.1.8. Perception of Carers roles and need for support

Both the professionals and the users were asked about caring arrangements and their perception of the carers' role and needs. It was believed that due to cultural specific reasons the Asian carers do not access all the services and support available to them e.g. "lack of knowledge /awareness about mental health could prevent families to understand the nature & extent of support required", or as another one said, "Because of the cultural backgrounds women and children end up doing most of the work", on the hand it was also believed that the extended family is a plus point. However it was also believed that 'due to fear of stigma they shy away from mental health services' and they tend not to integrate, there is much mis-understanding and confusion.

5.1.9 Over medication

The findings support the view that BME generally and South Asians are prescribed medication more than other alternative therapies, which was considered by some professionals as ‘cost effective and not requiring cultural sensitivity for long term interventions’.

5.1.10. Involvement of families and communities

There was overwhelming endorsement by the professionals for involving families and the community at large to tackling issues specific to the South Asian communities’ e.g. unless this ‘denial’ or breaking the taboos is dealt with by the South Asian communities, it was believed, that the mental ill health service users would not be able to access appropriate services nor will the professionals and the institutions be able to provide responsive services.

5.1.11. Views about 12 characteristics

The 12 characteristics i.e. the concerns and targets set in the DRE were also explored: some with the users and most with the professionals. There seems to be general consensus that those concerns were well founded e.g. disproportionate rate of compulsory detention, use of seclusion, higher rate of deaths in custody, higher level of violence, prevalence of fears and Asian specific fears e.g. fear of being judged, fear of being misunderstood. In some cases the clients have felt that mental health professionals would steer them away from religion.

5.2. Recommendations

The community engagement research project was designed to involve mental health service users as community researchers as well as participants to ascertain their experiences of mental health services in the Borough. The recommendations, listed hereunder, address both the communities and the service providers, individually with specific recommendations, and collectively, with recommendations applicable to both.

Therefore we begin by strongly recommending that:

5.2.1. Dissemination of research findings

To sustain a meaningful community engagement between the mental health service users, their families and the South Asian communities and the mental health services providers, both the North East Mental Health Trust, the Waltham Forest PCT and its partner agencies, particularly the DRE Steering Committee should facilitate to disseminate findings of this research project, and inform the DRE Steering Committee Action Plan accordingly.

Therefore it is recommended that the local DRE Steering Committee in collaboration with the Qalb Mental Health Centre should arrange a press/public launch to continue publicising the DRE Agenda, specially focusing on the following:

- ▶ 2010 Vision: the 12 Characteristics, highlighting the local situation i.e. local audit results generally and information relating to these 12 characteristics.
- ▶ Informing the local mental health services users and services providers' community about the local DRE Action plan so far and the future programme.

CULTURALLY COMPETENT SERVICES / COMMUNITY DEVELOPMENT

5.2.2. Socio-cultural and religious implications for cultural-competency

Based on the views expressed by various respondents, particularly the professionals, it is recommended the PCT as commissioning agency and NELMHT as provider should collectively consider ways and means of addressing some of the following issues and concerns to accommodate the religious, cultural and linguistic needs of a diverse South Asian Community in the Borough.

- ▶ Cultural competency in mental health services provision is much more profound than tokenistic gesture of providing prayer corners or meeting dietary requirements i.e. provision of halal food etc. Deep-rooted centuries old cultural and religious values, beliefs systems should be considered at diagnosis and treatment stages.
- ▶ Moreover there are specific circumstances, conditions and experiences of service users and their families, both in Britain and relating to back home, overwhelmingly endorsed by the professionals as contributory factors, which should be seriously considered at various stages by appropriate professionals, e.g. racism, discrimination, deprivation, isolation and home sickness, and un-/under employment.

Similarly the professionals have also identified a number of socio-cultural and religious factors, which, if considered, could alleviate mental ill health conditions e.g. religions, family & community support, culturally competent staff/nurses and cultural practices, dealing with language barriers, incorporating faith/culture in treatment, understanding cultural & religious identity and religious-cultural sensitive mental health promotion.

5.2.3. Faith sensitive services

There is general recognition that in case of some South Asian faith communities faith-sensitive services are more appropriate, therefore it is recommended that following among other aspects should be considered when planning faith-based therapies:

- ▶ Developing social facilities that are faiths sensitive
- ▶ Developing holistic family-centred support to include family religious practices
- ▶ Providing mental health awareness programmes from spiritual and faith perspective
- ▶ Training mental health workers to be more faith and culturally sensitive
- ▶ Advocating strategies to alleviate poverty/deprivation and tackle institutionalised religious discrimination

5.2.4. Medication and alternative therapies and wide ranging treatment

It is recommended that instead of heavy reliance on medication, wide ranging alternative therapies should be offered e.g.

- ▶ People who had used ‘talking therapies’ (e.g. psychologist, social worker, counsellor, user group) seemed generally happy with them.
- ▶ Religious and spiritual explanations and treatment for mental health problems were central to some of the participants’ understanding of mental health and to recovery.
- ▶ Availability of broader range of services (i.e. social inclusion – beyond medication). a greater range of help – someone to talk to who would understand – counsellors from minority ethnic backgrounds, self help and discussion groups.

5.2.5. DRE Agenda and Action plan

The whole DRE agenda and action plan; the job descriptions and work programme of the Community Development Worker(s) lead towards achieving responsive services, by engaging with the communities for their input and advising to build capacity within services provision, therefore without reiterating all that, we strongly recommend that the DRE implementation process should be informed by the findings of this community engagement project as well.

5.2.6. Hook on to what is already in existence

Prior to DRE, a number of policy drivers, e.g. Human Rights Legislation, Race Relation (Amendment) Act, 2000, among others had been influencing the equality agenda, therefore it is strongly recommended that all the existing initiatives should be integrated, where possible for a comprehensive and coordinated approach, e.g. the race equality impact assessment checklist, if there is one in existence, should be reviewed and adapted to incorporate DRE policy and practice implications.

5.2.7. Appropriate staffing

The need for more Asian staff has been stressed therefore it is recommended to appoint Asian staff with appropriate skills (linguistic and religious) and should be further trained to consider religious, cultural and spiritual needs of the Asians mental health service users.

The work of the Community Development Worker is well defined and articulated. There is likelihood that another CDW will be appointed, therefore it is strongly recommended that in view of the large South Asian community in the Borough, a post should be exclusively targeted for the Asian Community.

5.2.8. Training & (training the users' trainers)

The staff training and development programme should be designed to sustain community engagement for joint action planning and delivery, by involving the service users and their carers, as user consultants, as trainers and as provider of services as well. This should be achieved within the ethos of compliance with the Race Relations (Amendment) Act, 2000, addressing institutional racism, discrimination, and DRE in mental health care. South Asians service users should be trained as trainers to impart training to professionals.

5.2.9. Confidence & trust

The issue of confidence in a service provider remains a barrier in accessing and benefiting from the services. Confidence needs to be gained so that the Asian mental health service users should feel comfortable in sharing real life stories, which impact their mental health; therefore, it is recommended that professionals should be given deeper insight into deep-rooted cultural and religious characteristics, through recognition and commensurate training.

7.2.10. Suggestions for improvement

Throughout the text of this report a comprehensive list of suggestions for improvement are given by the professionals themselves, in different sections both directly and indirectly. It is recommended that their suggestions should be addressed systematically in conjunction with other valuable ideas.

7.2.11. Accessibility and advocacy

There is a need for greater and easier access to a wide range of health and social care services (including employment, housing etc.) and greater availability and access to interpreters for mental health service users and their carers.

It is recommended that capacity should be built within the voluntary sector, and they should be adequately resourced to provide service at par with mainstream services provision particularly dealing with advocacy and training and empowerment of Mental Health user communities (i.e. users, carers, advocates)

7.2.12. Public education among the Asian communities

It is recommended to deploy innovative means of creating awareness and educating the Asian community at large to combat guilt, stigma, and shame, so that they are empowered and are able to access services without being embarrassed and ashamed. Families, carers and the extended family members should be supported within the cultural and religious context. More and better information about mental health and mental health services – including in community languages, should be provided.

5.2.13. Partnerships Working

Mental health services providers should build stronger links and forge partnerships with faith organisations, to deliver better community education, reduce stigma, facilitate referral, and assist with prevention and recovery.

5.2.14. Combating specific fears

It is strongly recommended that community engagement programme, as it relates to the DRE building block, should consider genuine experiences of the Asian communities seriously and should not be dismissive. A list of specific fears has been highlighted by the users themselves and some professionals. These fears should be taken into consideration for effective services development and provision.

5.2.15. Mainstreaming versus targeted work

It is strongly recommended that any targeted service provision such as the Qalb Day Care or the Black Peoples' Mental Health, should be adequately supported and funded at par with any mainstream service provision, otherwise the targeted and dedicated services provision will always remain marginalised, ghettoised and second class service provision.

5.2.16. Role of Ethnic/Faith Media

There should be better use of local and ethnic press particularly the Asian media to promote mental health awareness and the positive work done by various institutions.

6. APPENDICES

APPENDIX A – USERS QUESTIONNAIRES

“USERS COMMUNITY” Questionnaire

No. _____

Age _____ Gender _____ Religion _____ User { } Carer { }

“USERS COMMUNITY” Questionnaire

DRE in Mental Health Care – The Qalb Community Engagement and Action Research Project re: South Asian communities as service users

Introduction

This research questionnaire is part of a Community Engagement Project conducted by The Qalb Centre, funded and supported by the National Institute of Mental Health in England (NIMHE) and the University of Lancashire (Uclan).

The project is part of the Black & Minority Ethnic (BME) Community Engagement programme.

The Qalb Centre is a registered charity that provides community based mental health support services to the Asian and other BME communities in the London Borough of Waltham Forest. The Qalb Centre has been established for nearly 13 years.

Aims of this Project & Questionnaire

The purpose of this questionnaire and project is to explore the extent and patterns of mental illnesses among the Asian communities, their perception of mental illness and signs and symptoms; their perception of barriers to accessing quality services and the overall experiences of those who have or using mental health services. The research will take into consideration culture, religion and languages when considering these issues.

We anticipate that the final outcomes of this research will inform and bring about improvements in the services BME communities receive.

All the Community Researchers are trained and supported members of the local community. As members of this community, we wish to request 40 mins of your time to kindly answer this questionnaire. We can assure you that any information collected is only for the purpose of the research and will be treated with the utmost **confidentiality**.

CONSENT FORM

This study is being conducted by the Qalb Centre and is about Mental Health issues within the Asian communities.

The aim of the Qalb Centre is to gain better understanding of the situation in Waltham Forest regarding users / their carers' experiences and their expectation of the services within cultural and religious contexts. A Report on the findings will be used to inform policy and also lobby for services that you tell us you need.

The findings of this research will also help inform mental health practitioners and allied workers of the mental health issues within Asian communities on a local level in Waltham Forest.

Please READ the declaration below, before agreeing to commence. If you wish please ask the researcher to read the declaration and explain it to you.

I understand:

The aims of the research and I have been free to ask any questions.

My participation is entirely voluntary and I can withdraw at any time.

I do NOT have to answer any questions if I wish not to but I am encouraged to answer where I can.

Any comments that I make will not be attributed to me unless I give consent.

All the information provided will be in confidence and it will only be shared amongst those working on the research, EXCEPT if I disclose information which reveals harms to others or child abuse – (This will be dealt with in accordance to The Qalb Centre disclosure procedure)

*I confirm I have read and understood this information sheet.
I agree to take part in the Qalb Centre Research Project.*

PART: I

Core Information

(1). Age last birthday:

- 16 – 18
- 19 – 21
- 22 – 24
- 25 – 29
- 30 – 39
- 40 – 49
- 50 +

(2). Gender:

- Male
- Female
- Transgendered or transsexual

(3). Ethnicity:

White

- British
- Irish
- Other (please explain)

.....

Mixed

- White and Black Caribbean
- White and Black African
- White and Asian
- Other (please explain)

.....

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Other (please explain)

.....

Black or Black British

- Caribbean
- African
- Other (please explain)

.....

Chinese or Other Group

- Chinese
- Other (please explain)

.....

- (4). Were you born in the UK: **Yes**
- No
-
- If no, how long have you lived here:** Less than 1 year
- 1 – 5 years
- 6 – 10 years
- 11 years or more
-
- (5). **Are you a:** British Citizen
- Refugee
- Asylum Seeker
- Other (please explain)
-
- (6). What is your first language?
- Spoken:** _____
- Written:** _____
- (7). **Which languages are you fluent in?**
- Spoken:** _____
- Written:** _____
- (8). **What is your religion:** None
- Christianity
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Other (please explain)
-
- (9). **Sexuality:** Lesbian or gay woman
- Homosexual or gay man
- Heterosexual or straight
- Bisexual
- Do not wish to answer
- Other (please explain)
-
- (10). **Do you have a disability:** Yes (please explain)
-
- No

Part: II

Personal experiences and perception of services received

(11) How would you describe mental ill health in your own words?

(12) Have you had any personal experience of mental ill health?

[Please tick ...]

YesNo

(13) Have you experienced any of the following? (Please tick all that apply)

- | | | |
|--------------------------------------------------|-------|--------------------------|
| 1. Depression | | <input type="checkbox"/> |
| 2. Guilt | | <input type="checkbox"/> |
| 3. Anxiety | | <input type="checkbox"/> |
| 4. Mood Swings | | <input type="checkbox"/> |
| 5. Suicidal thoughts | | <input type="checkbox"/> |
| 6. Suicide attempts | | <input type="checkbox"/> |
| 7. Headaches/ Migraine | | <input type="checkbox"/> |
| 8. Intrusive thoughts | | <input type="checkbox"/> |
| 9. Flashbacks | | <input type="checkbox"/> |
| 10. Nightmares | | <input type="checkbox"/> |
| 11. Difficulties sleeping | | <input type="checkbox"/> |
| 12. Emotional numbness/withdrawal..... | | <input type="checkbox"/> |
| 13. Loss of appetite | | <input type="checkbox"/> |
| 14. Drinking too much alcohol or taking drugs... | | <input type="checkbox"/> |
| 15. Relationship difficulties | | <input type="checkbox"/> |
| 16. Poor concentration | | <input type="checkbox"/> |
| 17. Memory loss | | <input type="checkbox"/> |
| 18. Aches | | <input type="checkbox"/> |
| 19. Emotional Pain: | | <input type="checkbox"/> |
| 20. Physical Pain | | <input type="checkbox"/> |
| 21. Other: _____ | | <input type="checkbox"/> |

(14) Could you kindly indicate which of the following conditions have you experienced?

- | | |
|----------------------------------------|-----|
| 1. Schizophrenia..... | [] |
| 2. Bipolar disorder..... | [] |
| 3. Obsessive-compulsive disorders..... | [] |
| 4. Ante natal depression..... | [] |
| 5. Post natal depression..... | [] |
| 6. Psychotic episodes..... | [] |

- 7. Eating disorders e.g. Bulimia, Anorexia Nervosa)..... []
- 8. Agoraphobia..... []
- 9. Depression..... []
- 10. Personality disorder..... []
- 10. Borderline personality disorder []
- 11. Panic and other severe anxiety disorder..... []
- 12. Attention deficit/hyperactivity disorder..... []
- 13. Acute stress disorder..... []
- 14. Delusional disorder..... []
- 15. Nightmare disorder..... []
- 16. Any other

(15) Do you feel any of the following factors may have contributed to your mental ill? health? (In the UK)

(Please indicate by putting a tick in the boxes that apply to you)

- 1. Detention (by immigration or police etc) []
- 2. Homelessness []
- 3. Overcrowding []
- 4. Family problems []
- 5. Poverty []
- 6. Separation from family /friends []
- 7. Violence []
- 8. Racial abuse (physical or verbal) []
- 9. Racial discrimination (in school/employment/treatment) []
- 10. Unemployment []
- 11. Uncertainty about your legal status []
- 12. Social isolation []
- 13. Language difficulties []
- 14. Sexual assault []
- 15. Rape []
- 16. Domestic violence []
- 17. Serious illness (Physical) []
- 18. Financial problems []
- 19. Physical disability []
- 20. Eating disorder []
- 21. Drug Abuse []
- 22. Lack of Education / qualification []
- 23. Over qualification []
- 24. Other (Please specify) _____ []

SERVICES AND TREATMENT

(16) Did you seek any support for your mental health issues?

Yes() No..... ()

Please explain what kind of support (if Yes) _____

If No, why not?_____

(17) In which setting did you come into contact with mental health services?

[Please tick as many as apply]

- a)..Primary care (for example, GPs, community services etc?) ()
- b)..Hospital care ()
 - b.1. Stoneleigh[]
 - b.2. Nasebury Court []
 - b.3. Claybury..... []
 - b.4. Goodmayes []
- c) ..Specialist mental health services (for example psychiatric hospital or out-patient clinic).....()
 - c.1. Qalb Centre.....[]
 - c.2. Larkswood..... []
 - c.3. South Forest Centre..... []
 - c.4. Ferguson Centre..... []
 - c.5.Other [please describe] ()

(18) Is your experience of using the services, based on?

- a) Using services yourself Yes.....No.....
- b) Caring for a friend or relativeYes.....No.....
who has used mental health services
- c) Other [please describe]

(19) Overall, how would you rate the quality of your experience in these settings?

[Please tick ...]

Very poor.....Poor.....Average.....Good.....Very Good.....

PERSPECTIVE ON CARING

(20) Do you care for anyone with Mental Health issues? Yes.....No.....

(21) Do you know anyone who is a carer or has cared? Yes.....No.....

(22) What are the needs, if any, of a carer of a mental health service user?

Please explain.....

(23) Are you aware of any support one can get as a carer?

Yes.....No.....Do no know

Please describe _____

(24) Can you describe how do Asian carers feel, if they have to care for some one in the family with mental ill health?

IMPROVEMENT OF SERVICES

Please give answers to the following if you think these have created any problem for you, as an Asian or someone you know, in getting better mental health services.

(25). Have you experienced language barriers when receiving services?

YesNo.....Don't know

Say when and how _____

(26). Have you ever felt that you were treated differently because of your ethnicity i.e. religion, languages, culture, colour?

Yes.....NoI don't know

By staff _____

By system _____

By other? _____

Please describe the patterns and extent such differential treatment.

Extent: Very high.....High.....Some.....No.....

Pattern: Have you experienced any of the following?

- Patronizing attitudes.....Yes.....No.....DK.....
- Lack of understandingYes.....No.....DK.....
about Asian value system
- Verbal abuse (racial).....Yes.....No.....DK.....
- Physical abuse(racial).....Yes.....No.....DK.....
- Discriminatory treatment.....Yes.....No.....DK.....

(27) Do you think enough is being done by local government agencies to improve mental health services for the Asian communities.

YesNo.....Don't know

If Yes, what is being done?_____

If No, why do you think it is so_____

(28) What other improvements can be made

Part: III

Perception of Culturally competent service

(29)Do you consider that the services, which you are receiving or have received, were culturally and religiously sensitive?

Yes..... () No..... Partially..... () I do not know ()

Could you kindly give reasons in support of your answer i.e. if yes, what was cultural and religious about them and how did you notice and if no, why do you say that?

(30). In your opinion what is the best treatment for you in the light of your conditions?

Please explain_____

Or do you consider the professionals know what is best for your mental health needs.

Yes.....No.....Sometimes.....I don't know.....

(31). Do you feel comfortable disclosing your mental health issues to professionals?

- Never..... ()
- Some times.....()
- All the times..... ()
- Depends on the situation..... ()

Please give reasons for your answer _____

(32) Could you kindly indicate if you are already receiving the following and if not please tick what would you like to receive?

	Already receiving	Would like to receive
1. Support of relatives and friends	[]	[]
2. Medication.....	[]	[]
3. Counselling.....	[]	[]
4. Psycho-therapy.....	[]	[]
5. Information.....	[]	[]
6. Spiritual support.....	[]	[]
7. Drop-ins.....	[]	[]
8. Help from others in the same position.....	[]	[]
9. General practitioner.....	[]	[]
10. Befriending.....	[]	[]
11. Hospital.....	[]	[]
12. Support worker.....	[]	[]
13. psycho-education/guided self help	[]	[]
14 Alternative therapies e.g.		
⇒ Massage	[]	[]
⇒ Aromotherapy	[]	[]
Other (please specify) _____	[]	[]

Part: V

2010 Fit for purpose

Here under you will notice some characterises, which the Government believes impact adversely on Black and Ethnic minority communities, disproportionately more than the rest of the population. Could you kindly give your views whether it is correct and how best to improve the situation?

(33) Asian communities have their own type of **fears** as listed below: Please tick if you

agree and add any more.

1. **Fear** that the family and the community will find out..... ()
2. **Fear** that mental health issues will lessen the prospects of job opportunities..... ()
3. **Fear** that mental health issues will lessen the chances of getting married..... ()
4. **Fear** that the individual and family will be labelled as mad.....()
5. **Fear** of getting sectioned and detained in hospital..... ()
6. **Fear** of too much medication..... ()
7. **Fear** of getting arrested by the police..... ()
8. **Fear** of people finding out about confidential information about you..... ()
9. **Fear** of not being properly understood by the service providers.....()
10. **Fear** of sent back, by parents, to country of origin to hide the problem.....()
11. **Fear** of failing the family and the community.....()

(34) Could you describe your experiences of the care and services you received at following stages: (applicable to users/carers only) by putting a circle around.

(a) Referral by GP or any other sources.	Bad	Very Bad	Good	Very Good
(b) Diagnosis and assessment...	Bad	Very Bad	Good	Very Good
(c) Type of treatment received (as in-patient)	Bad	Very Bad	Good	Very Good

(35) Could you describe the type of help/treatment you received when discharged (on CPA)

(36) Were you satisfied with the facilities provided after discharge?

Yes.....No..... I did not know my options.....

Please explain your reasons if Yes, Why_____

If No, Why not_____

What could have been done differently?_____

(37) Do you think it is possible to **recover** from mental illness?

Can recover fully Yes () No. () Some times ()

Can recover partially Yes () No. () Some times ()

Can never recover Yes () No. () Some times ()

(38) How can you tell if some has recovered from the mental illness (Could please list some signs of recovered conditions) _____

(39) If mental health patients are involved with the police, they end up in **prison**:

Yes () No. () Not always ()

(40) If yes: how could this be avoided and reduce the numbers in prisons;

Please make some suggestions _____

(41) It is generally believed that BME mental health patients are given more drugs than **other therapies**. Do you agree with this?

Yes () No. () DK ()

If yes: why do you think it is? _____

And what other culturally appropriate services could be provided: Please list the range of treatments and therapies, which would help _____

(42) Would you like to add any thing else which has not been covered so far?

To be collected (after completion) by:

Name of researcher _____ **Phone No.** _____

THANK YOU for you support

APPENDIX 2 –PROFESSIONAL QUESTIONNAIRE

Professional Questionnaire

No. _____ **Job & Organisation** _____

Gender _____ **Ethnicity** _____ **Religion** _____

DRE in Mental Health Care – The Qalb Community
Engagement and Action Research Project re: Mental Health
issues of South Asian communities Service Users

Professional Questionnaire

Introduction

This research questionnaire is part of a Community Engagement Project conducted by The Qalb Centre, funded and supported by the National Institute of Mental Health in England (NIMHE) and managed by the University of Lancashire ([Uclan](#))

The Qalb Centre is a registered charity that provides community based mental health support services to the Asian and other BME communities in the London Borough of Waltham Forest. The Qalb Centre has been established for nearly 13 years.

Aims of this Project & Questionnaire

The purpose of this questionnaire and project is to explore the extent and patterns of mental illnesses among the South Asian communities, their perception of mental illness and signs and symptoms; their perception of barriers to accessing quality services and the overall experiences of those who have used or currently using mental health services. The research will take into consideration culture, religion and languages when considering these issues.

We anticipate that the final outcomes of this research will inform and bring about improvements in the services BME communities receive. **The findings of the research**

will also help inform mental health practitioners and allied workers of the mental health issues within the Asian communities on a local level in Waltham Forest.

All the Community Researchers are trained and supported members of the local community. As members of this community, we wish to request 40 minutes of your time to kindly answer this questionnaire. We can assure you that any information collected is only for the purpose of the research and will be treated with the utmost **confidentiality**.

We understand that the views expressed by you are on behalf of the organisation you are working, but based on your personal experiences.

Part I

Core Information

(1). Gender:	Male	<input type="checkbox"/>
	Female	<input type="checkbox"/>
(2). Ethnicity:	White	
	British	<input type="checkbox"/>
	Irish	<input type="checkbox"/>
	Other (please explain)	<input type="checkbox"/>
	
	Mixed	
	White and Black Caribbean	<input type="checkbox"/>
	White and Black African	<input type="checkbox"/>
	White and Asian	<input type="checkbox"/>
	Other (please explain)	<input type="checkbox"/>
	
	Asian or Asian British	
	Indian	<input type="checkbox"/>
	Pakistani	<input type="checkbox"/>
	Bangladeshi	<input type="checkbox"/>
	Other (please explain)	<input type="checkbox"/>
	
	Black or Black British	
	Caribbean	<input type="checkbox"/>
	African	<input type="checkbox"/>
	Other (please explain)	<input type="checkbox"/>
	
	Chinese or Other Group	
	Chinese	<input type="checkbox"/>
	Other (please explain)	<input type="checkbox"/>
	

(3). Besides English what other languages can you:

Speak:_____.

Write_____

Read:_____

- (4). **What is your religion:**
- | | |
|------------------------|--------------------------|
| None | <input type="checkbox"/> |
| Christianity | <input type="checkbox"/> |
| Buddhist | <input type="checkbox"/> |
| Hindu | <input type="checkbox"/> |
| Jewish | <input type="checkbox"/> |
| Muslim | <input type="checkbox"/> |
| Sikh | <input type="checkbox"/> |
| Other (please explain) | <input type="checkbox"/> |
| | |

- (5) Name of your agency/Department/Institution egg. Goodmays Hospital or name the Vol. organization (or preferred provider etc.)

- (6) Your specific Role/job e.g.

Your Job Tile_____.

Nature of your work e.g.

1. Policy Development_____.

2. Training / Recruitment_____

3. Face Work_____

4. Any other_____

Part II

(7) According to your analysis could you kindly state whether any of the following factors tend to contribute proportionately more, compared with the rest of the population, to the mental illness of the South Asian mental health service users?

Kindly rate your assessment on a scale of 1 to 5: 5 being greatest influence. Please put a number: 1 to 5 in the box or circle the No.

- 4.3. *Out patient experiences* [] 1...2...3...4...5...
- 4.4. *In patients experiences* [] 1...2...3...4...5...
- 4.5. *Counselling* [] 1...2...3...4...5...
- 4.6. *Clinics*..... [] 1...2...3...4...5...
- 4.7. *Hospitals*..... [] 1...2...3...4...5...
- 4.8. *Medication* [] 1...2...3...4...5...
- 4.9. *Kindly list any other relevant factors to do with Internal Environment* or ADD any comments please.

5. Day Care and rehabilitation Environment Contributes

- 5.1. *Type of staffing*[] 1...2...3...4...5.....
- 5.2. *Type of activities*[] 1...2...3...4...5.....
- 5.3. *Type of facilities and resources*.....[] 1...2...3...4...5.....

5.4. . *Kindly list any other relevant factors to do with Care and Rehabilitation Environment* or ADD any other comments please

(8) Could you also list any factors / aspects which are specific to Asian cultures, religions and languages that might help recovery?

- 1.2.
- 3.4.
- 5.6.
- 7.8.

(9) In your opinion are there any specific patterns of mental illness among the Asian communities e.g. certain types of disorders and mental illnesses more common among the Asians than other groups.

- Yes.....()
- No.....()
- Don't know ()

(a) If Yes, could you kindly list some of those illnesses and disorders _____

(b) Could you also explain why this could be so _____

Perspective on Caring in the Family

(10) What are your views about the quality of caring for users of mental services within the Asian families?

(11) What are the needs, if any, of an Asian carer of a mental health service user?

Please explain _____

(12) Can you kindly describe the kind of support available to the carers generally?

Please describe _____

(13) Do think Asian carers are accessing the support, they need?

Yes.....No.....Do no know.....

Please explain _____

(14) In you view, how do Asian carers feel if they have to care for some one in the family with mental ill health?

Part III
Perception of cultural competent service

(15) Could you kindly describe in your own words a culturally competent mental health service provision relevant to the South Asian communities?

(16) Do you consider that the services provided by NELMHT are culturally competent?

i. Yes... () ii.No.....() iii.Somewhat culturally competent.....() iv. I don't know..()

Could you kindly give reasons in support of your answer ie if yes, how and what and if no, why not?

(17) These days there is a great deal of emphasis on “values based practice in mental health”. Do you consider that there are any specific considerations for “Asian values and belief systems” in this context.

Yes.....No.....I do not know.....

Please give reasons for your answers or indicate any specific considerations _____

(18) Do you agree that the Asian communities are reluctant to share culture specific and domestic issues and information with mental health professionals?

YesNo.....Some times.....Don't know

Please give reasons for your answers _____

Part IV

Your views on the Inside Outside Report

(19) Are you aware of the Inside Outside Report?

Never heard of it..... []

I have heard of it..... []

I am addressing the issues in the report..... []

Do not know what is in the report..... []

The Inside/Outside report proposes a number of changes to current mental health services. These are meant to improve the services available for people from minority ethnic groups. Three of the main proposals are described below. Could you tick how important these proposals are in improving services?

a) The plan proposes that training of staff on cultural awareness and competency is an important goal. How do you rate this goal?

[Please tick ..]

- Not important[]
- Fairly important[]
- Important[]
- Very important[]
- Don't know[]

b) The plan proposes a number of changes to be sensitive to ethnic differences in the care and services delivery. How important do you feel these changes are?

[Please tick ..]

- Not important[]
- Fairly important[]
- Important[]
- Very important[]
- Don't know[]

c) The plan proposes that black and minority ethnic communities themselves need further help and assistance in dealing with mental health issues in their own communities alongside existing mental health services. How important do you feel is such? community development for improving mental health in the community.

[Please tick ..]

- Not important[]
- Fairly important[]
- Important[]
- Very important[]
- Don't know[]

(20) Overall, do you feel that the plans, if put in action, will improve mental health services for people from ethnic minority groups? [Please tick ...]

- Yes[]
- No[]
- Don't know[]

Part V

2010 Fit for purpose

The DRE in Mental Health Care – a five year action plan proposes a number of changes to current mental health services. These are meant to improve the services available for people from minority ethnic groups. Please answer the following by putting a tick.

- i. I have not heard about DRE in Mental Health Care.....[]
- ii. I have heard about DRE in Mental Health Care.....[]
- iii. I am not sure what is in DRE in Mental Health Care.....[]
- iv. I am involved in implementation of DRE.....[]

Here under you will notice a number of characterises, which the Government believes impact Black and Ethnic minorities communities, adversely, disproportionately more than the rest of the population. Could you kindly give your views whether it is correct and how best to improve the situation?

(21) Fear of mental health care and services

21.1 Could you kindly list what types of **fear** of mental health care and service, the BME users of the service have?

21.2 Could you kindly list the basis of such **Fears**, according to your knowledge/experiences?

21.3 Could you kindly suggest how these **Fears** could be reduced and by whom?

(a) Who can reduce_____

(b) How these fears can be reduced_____

(22) It is generally believed that there are disproportionately higher rates of admission to psychiatric inpatients units from BME communities.

I agree.....[]
Do not agree..... []
Don't Know..... []

If you agree, could you kindly suggest how these admissions could be reduced.....

(23) Why do you think some patients get violent?_____

(24) How do such violent incidents could be controlled_____

(25) It is generally believed that there are disproportionately higher rates of compulsory detention in inpatient units from BME communities

I agree.....[]
Do not agree..... []
Don't Know.....[]

If you agree, could you kindly suggest how compulsory detention could be reduced...

(26) It is generally believed there are disproportionately higher rates of use of seclusion from BME communities.

I agree.....[]
Do not agree..... []
Don't Know..... []

If you agree, could you kindly suggest how to reduce use of seclusion_____

(27) It is generally believed that there more Deaths in mental health services following physical interventions with BME communities.

I agree.....[]

Do not agree..... []

Don't Know.....[]

If you agree, could you kindly suggest how these deaths could be avoided_____

(28) If mental health patients are involved with the police, they end of in the prison:

Yes () No. () Not always ()

(29) If yes: how this could be avoided and reduce the numbers in prisons;

Please make some suggestions_____

(30) It is generally believed that BME mental health patients are given more drugs than other therapies Yes () No. () I do not know ()

If yes: why do you think it is? _____

And what other culturally appropriate services could be provided: Please list the range of treatments and therapies, which could help_____

(31) It is believed that BME communities and BME service users can help in training the mental health staff:

(a) Please say who in the communities can do such training_____

and how this can be done?_____

(b) Could you list what should be included in this training about the BME communities?

(c) Could you please say how the BME service users contribute to this training_____?

(32) It is suggested that the BME services users should be involved/consulted in designing, developing and delivering the services. Could you kindly give your views how this could be done.

(a) Designing of services_____

(b) Developing of services_____

(c) Delivering of services_____

(33) If it is considered to recruit a workforce to deliver services for BME communities, what kind of professionals would you like to recommend being in that workforce.

(a) Their skills_____

(b) Their personal qualities_____

(c) Their backgrounds_____

To be collected (after completion) by:

Name of researcher_____

Telephone No_____

THANK YOU FOR YOUR SUPPORT

APPENDIX 3- Application for ethical approval Section 1

Centre for Ethnicity and Health – Application for Ethical Approval	
Name of Group	The Qalb Mental Health Centre
Address	Low Hall Lane, Walthamstow E17
Name of Support Worker	Imran Mirza
Date:	5.8.2006 Resubmitted 14.10.2006

Section 2:

<p>What kind of work does the group intend to do as part of this project?</p>	<p>Aim:</p> <p>We intend to look at the mental health needs of South Asian mental health service-users in Waltham Forest, and comment on the appropriateness of the services (based on evidence) with regard to faiths, cultures and diversity generally and suggest how to improve.</p> <p>Therefore the key objectives of the project are:</p> <p>(a) ‘To highlight the service experiences of BME mental health service users and their carers’.</p> <p>(b) In the light of (a) above, to make recommendations that will contribute to the delivery of better mental health services for BME communities in line with <i>Delivering Race Equality in Mental Health Care</i>-specifically we want to make recommendations about ensuring</p> <ul style="list-style-type: none"> ▶ Equality of access ▶ Equality of experience and ▶ Equality of outcomes <p>for South Asian mental health service users and their carers.</p> <p>(c) To work closely with key stakeholders in the Focused Implementation Sites towards making Delivering Race Equality. happen on the ground</p> <p>(d) To empower and facilitate mental health service users and their carer (as workers</p>
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	<p>/researchers and volunteers) in engaging with mental health service providers to voice their needs in shaping the mental service provided for them which are appropriate to their needs.</p> <p>(e) The group intends to develop questionnaire (s) to be completed by existing Qalb Centre Day Care users, and other services user as advised by the Steering Committee members, and some professionals, as guided by the Steering Committee members. (Separate request is being made to the Local Research Ethics Committee (North East London Mental Health Trust)</p> <p>Questionnaires will be completed by members of the research team who will ask respondents the questions and make notes as they interview them, for those who cannot write themselves. Those who are able to write they will be given the questionnaire to complete themselves in the presence of the researcher(s).</p> <p>The researchers will work in pairs. One asking questions and other one taking the notes With the permission of the interviewee the session(s) will be tape recorded, to double check any important points made during the process. .</p> <p>(f) A half day seminar and launch to be attended by at least 50 individuals and representatives of services to inform the research process. (This was held on 27th July and a comprehensive report has been prepared). Some issues raised at the seminar will be incorporated in the final report, as appropriate.</p> <p>(g) Review of relevant literature will be carried out related to 12 characteristics of 2010 vision. A great deal of information is being collected by the sub committee of the Local Implementation Team and North East London Cluster group, as part of their action plans. The research coordinator and the Director of the Qalb Centre have access to all their papers, as members of these groups, therefore any information gathering will be built upon, what is already available to avoid duplication.</p>
How do they intend to do	Appoint community researchers, who are mental

<p>this?</p>	<p>health services users and key mental health workers, associated with the Qalb Centre and similar institutions.</p> <ul style="list-style-type: none"> i. Focus Group meetings – three: one with five therapists working for the Qalb Centre, and one each with women and men, who attend the Qalb Day Care Centre. (not more than 5 in a group) ii. Questionnaires: 60 questionnaires will be completed by the services users, those who attend the Qalb Day Care Centre and the Ferguson Day Care Centre. The method of questionnaire completion has already been mentioned above. iii. Steering Committee to oversee and support (the 6th draft of the user questionnaire and 3rd draft of professional questionnaire has already been circulated to the all the steering committee members for their comments: sent by the PCT i.e. the Steering Committee lead). A small group of steering committee members have agreed to meet with the coordinator face to face to go over the questionnaires and provide further advice regarding sample etc. iv. Meet with the support worker and PCT and the Mental Health Trust officials regularly. v. Review secondary research relevant to South Asians and the Mental Health issues. vi. Attend training provided by the University.
<p>Who will the respondents be?</p>	<p>For Focus Groups: Users of the mental health those attending rehabilitation programmes (those who have been through the system) – of all ages over the age of 16 both male and female and a cross section of Asian communities.</p>

	<p>For Questionnaires: 60 individuals male/female services users will be requested to complete a questionnaire.</p> <p>A separate questionnaire will be given to at least 20 professionals representing various care pathways who will also be requested to complete a questionnaire. Members of the steering committee represent various services at both policy and face work level and they have agreed to complete the questionnaire. Some service managers who are on the Steering Committee have also agreed to recommend other professionals who will be appropriate to complete the questionnaire.</p>
<p>Who will they get to do the work?</p>	<p>Eight researchers: 5 male and 3 female, have been recruited. Five of the eight are service users and two are key-workers, representing a cross of the Asian communities.</p> <ul style="list-style-type: none"> ○ Sending circular letter to local groups advertising the vacancies and the project ○ By approaching potential individuals and groups and encourage them to apply
<p>Where they will undertake the work?</p>	<p>In London Borough of Waltham Forest – all the four districts i.e. Leyton, Leytonstone, Walthamstow and Chingford.</p> <p>The Qalb Day Care Centre and Ferguson Mental Health Centre will be used to contact potential respondents.</p>
<p>How will those who are doing the work be supported and supervised?</p>	<ul style="list-style-type: none"> i) Fortnightly meetings with support worker. ii) Regular contacts/meetings with the coordinator. iii) Training provided by the University. iv) Support by the steering committee members. <p>The 7 community researchers will all work to the Research Co-ordinator and the Director of the Qalb Centre.</p> <p>Both of them will oversee the project on a day to day basis. The Co-ordinator will meet with the team both individually and as a team once a week, and will also contact all of them by e-mail.</p>

	All the researchers will be attending the training workshops that the University is providing.
How they will ensure that participants in the project have given consent? You should have an information sheet about the project which is read out and given to potential participants which explains to them (a) what the project is about. (b) that participation is voluntary (c) what will happen to the information that they provide (d) that they can stop the interview at any time and (e) that they do not have to answer any questions that they do not want to.	<p>Explaining to them both orally and in writing (a sheet is included at the beginning of the questionnaire, which will be read to them or they can read themselves)</p> <p>APPENDIX A: An information sheet about the project has been prepared separately, which is included in after the introductory page in the questionnaires (See Appendix A). The interviewers will read this to potential respondents before they begin completing the questionnaire. Respondents will be asked whether they are happy to proceed with the interview/completion of the questionnaire, based on the information that they have been given.</p>
Please enclose the information sheet and confirm that it addresses issues (a), (b), (c), (d) and (e) above	<p>Information sheet enclosed (yes) tick to confirm</p> <p>Issue (a) covered (yes) tick to confirm Issue (b) covered (yes) tick to confirm Issue (c) covered (yes) tick to confirm Issue (d) covered (yes) tick to confirm Issue (e) covered (yes) tick to confirm</p>
How they will the project ensure confidentiality? Note: you will not usually need to know (or collect) the names or addresses of respondents. If you know them already, or if you are going to ask people their names as a matter of courtesy, these should not be recorded on the questionnaires or the notes that relate to the interview.	<p>Their names will not be known or sought and personal details will not be linked to any individual. They will not be asked to sign the consent form.</p> <p>Interviews will be conducted in private rooms within the Centre or any other appropriate place. Completed questionnaires will be stored in a locked filing cabinet in an office within the centre. Only staff working on the project will have access to them. If the questionnaire is completed elsewhere, i.e. not at the Qalb Centre site, then the researchers will be required to transport the questionnaire back to the site as quickly as possible and kept in the filing cabinet. If transportation facilities are needed these will be provided to the researcher, if public transport is deemed inadequate. The completed questionnaires will not be left in the cars, brief cases or taken home by the</p>

<p>Note: you cannot guarantee confidentiality to anyone taking part in a focus group. You can request that people keep things within the group, but you cannot guarantee that they will. This must be made clear to people who agree to participate in focus groups.</p>	<p>researchers.</p> <p>Data from the questionnaires will be analysed and presented in the final report (and any interim reports) in such a way to ensure that it is not possible to attribute any particular response to any specific individual. Tape recording notes and completed questionnaires from the research project will be destroyed once the final report has been completed.</p> <p>The names of participants/respondents will not be revealed to anyone outside of the research team.</p>
<p>How will data generated by the project be handled and stored?</p>	<p>Completed questionnaires and notes from focus groups/interviews will be stored in a locked filing cabinet in an office within the centre. Only staff working on the project will have access to them. All interview notes/questionnaires will be destroyed by shredding once the final report has been written and accepted – all interviews, conversations and focus group discussions tapes will be destroyed.</p>
<p>What risks are there? How will risks be identified and managed?</p> <p>Note you need to think about risks to researcher and volunteers and risks to participants. For some people, simply taking part in the research may be a risk (e.g. if the parent of a young Muslim woman finds out that she has been talking to someone about drugs). For others, particular situations may be risky (e.g. if you are using ex-drug users to work on the project, are you putting them at risk of relapse by asking them to go back</p>	<p>There are risks involved both to the researchers and the respondents, e.g.</p> <ul style="list-style-type: none"> ▶ The researchers safety and security ▶ Emotional distress caused to the respondents ▶ Distress caused to the researchers who are service users themselves ▶ Security and confidentiality of the data collected and keeping the information safe and secure ▶ Danger of working with violent patients ▶ Privacy and location of venue where data will be collected ▶ Consent by the participant to participate or withdraw at any time ▶ Ensuring anonymity <p>A number of opportunities exist to identify possible risks: individual workers may identify them on their own; they may be identified as part of weekly team meetings; they may be identified during discussion</p>

<p>into situations where drugs are being sold or used? If something gets stolen from an office, will they get blamed for it [regardless of whether or not they did it] because everyone knows they are a drug user?). Are the interviewees particularly vulnerable or frail? Are interviewers likely to be vulnerable to allegations of misconduct?</p> <p>Are the risks of carrying out or participating in individual interviews different from those of taking part or running a focus group? They probably are, and you need to show that you have thought about and addressed this.</p> <p>THIS IS ONE OF THE MOST IMPORTANT SECTIONS OF THE FORM. YOU MUST THINK CAREFULLY ABOUT WHAT THE POSSIBLE RISKS ARE AND ABOUT WHAT STEPS CAN BE TAKEN TO REDUCE AND MANAGE THEM. THE ETHICS COMMITTEE UNDERSTANDS THAT IT IS USUALLY IMPOSSIBLE TO ERADICATE EVERY</p>	<p>with the support worker; they may be identified at Steering Group meetings. Where any risk is identified it will be the responsibility of the Project Co-ordinator to ensure that measures are taken to manage the risk appropriately. The research team will be supported in doing this by the Support Worker, the Steering Group and their own line management structure within the Qalb Centre offices.</p> <p>How to manage:</p> <p>i) To establish confidentiality clause and ground rule within the team, Steering Committee and other individual and group meetings.</p> <p>(ii) There is also the risk for researchers safety which will be managed by creating awareness about potential hazards and ensuring that they work in pairs, particularly female researchers.</p> <p>(iii) In order to control risks, the interviewers will not be expected to visit homes of potential respondents for completion of questionnaires or to do with any aspect of the research project.</p> <p>(iv) The consent form will be read to the participants and they will be assured about the anonymity.</p> <p>(v) The Qalb Mental Health Centre has agreed to provide emotional support, free of charge, by their qualified therapists and counsellors in case of any emotional distress either to the participants or the researchers.</p> <p>(vi) The Director of the Qalb Centre and the Manager of Ferguson Centre will be asked to advise on how to approach the potential respondents, with particular reference to any violent history of the respondents. If someone is known to have a history of violence they will not be interviewed.</p> <p>(vii) Since researchers could not be told about the backgrounds of the potential participant because of ethical issues, the agencies will be requested not to recommend any patients who are known to be violent or dangerous.</p>
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<p>RISK, BUT THE ETHICS COMMITTEE MUST BE SATISFIED THAT ANY RISKS ARE REASONABLE, AND THAT STEPS HAVE BEEN TAKEN TO MINIMISE THEM</p>	<p>(viii) The research team will be guided by the guidelines given by the local PCT/Mental Health Trust Ethic Committee about any local Mental Health Institutions.</p> <p>(xi) Every effort will be made to address the issues of safety and risk management to do with potential respondents and their conditions and the researchers, who themselves are service users.</p> <p>A specific meeting of the team will be devoted to the risk management before the team embarks on data collection.</p>
<p>Please confirm the make up of the steering group</p>	<p>Before the research project commenced, a DRE Steering committee was already in existence. It was decided at their meeting in May that the DRE Steering Committee will serve as a Steering Committee for the project as well.</p> <p>At the request of the steering committee a special paper was presented to highlight the focus of the research and to link the work of the steering group with the work of the research project. At every six weekly meetings the project coordinates presents progress reports and seeks further guidance from the members. A great deal of contacts are made via e-mail in between the six weekly meetings to check at every stage for the focus of the project. The Uclan Support worker is copied all this correspondence. Three particular members of the steering committee, who represent North East London Mental Health Trust on the Steering Group are taking keen interest and guiding what kind of information is required to contribute to their action plan. These individuals include the Community Development Worker, the Diversity Manager and their Manager. They are looking at the questionnaire and will sort out the approval from the Ethnics Committee once the questionnaire(s) have been finalised. (The special report prepared at their request is attached as Appendix D.)</p> <p>Please see attached: APPENDIX B for Terms of reference of the Steering Committee including membership list. Specimen agenda (27.7.2006 meeting) and Minutes</p>

	of the meeting held on 16.6.2006 (Appendix C).
How often does the Steering Group meet? It needs to meet often enough to both guide the research and keep it on track, and to pick up on any ethical issues that may arise.	Six weekly
Is the Steering Group clear that it has a responsibility for helping to manage the ethical issues that may arise as a result of running this project?	Yes – Actually a separate request has been made to the local PCT/Mental Health Trust Ethics Committee to seek their approval to access potential respondents and seek their guidance around risk management. They are now waiting for the final versions of the questionnaire. Once the approval from Uclan is granted, they will be given all the relevant information.

Section 3: To Be Completed By UCLan internal ethics committee

Date received:	
Reviewed by:	<i>Jez Buffin, Jane Fountain</i>
Decision:	

APPENDIX (A)

“USERS COMMUNITY” Questionnaire

DRE in Mental Health Care – The Qalb Community Engagement and Action Research Project re: South Asian communities as service users

Introduction

This research questionnaire is part of a Community Engagement Project conducted by The Qalb Centre, funded and supported by the National Institute of Mental Health in England (NIMHE) and the University of Lancashire (UCLAN).

The project is part of the Black & Minority Ethnic (BME) Community Engagement programme.

The Qalb Centre is a registered charity that provides community based mental health support services to the Asian and other BME communities in the London Borough of Waltham Forest. The Qalb Centre has been established for nearly 13 years.

Aims of this Project & Questionnaire

The purpose of this questionnaire and project is to explore the extent and patterns of the mental illnesses among the Asian communities; their perception of mental illness and signs and symptoms; their perception of barriers to accessing quality services; and the overall experiences of the mental health services users. The research will take into consideration culture, religion and languages when considering these issues.

We anticipate that the final outcomes of this research will inform and bring about improvements in the services BME communities receive.

All the community researchers are trained and supported members of the local community. As members of this community we wish to request 40 minutes of your time to kindly answer this questionnaire. We can assure you that any information collected is only for the purpose of the research and will be treated with the utmost

CONFIDENTIALITY.

.....

CONSENT FORM

This study is being conducted by the Qalb Centre and is about Mental Health issues within the Asian communities.

The aim of the Qalb Centre is to gain better understanding of the situation in Waltham Forest regarding the users / their carers' experiences and their expectation of the services within cultural and religious contexts. A report on the findings will be used to inform policy and also lobby for services for services that you tell us you need.

Please READ the declaration below and ask the researcher to explain it to you, if any points are not clear.

I have been requested to participate in this study and voluntarily accept.

I understand:

The aims of the research and I have been free to ask any questions.

My participation is entirely voluntary and I can withdraw at any time.

I do NOT have to answer any questions if I wish not to, but I am encouraged to answer where I can.

Any comments that I make will not be attributed to me. [we have taken 'unless I give consent' out].

All the information provided will be in confidence and it will only be shared amongst those working on the research, EXCEPT if I disclose information which reveals serious harms to me or others (including child abuse) – (This will be dealt with in accordance to The Qalb Centre disclosure procedure)

I am happy for the interview to be taped so that the research team can check what has been said afterwards. I understand that the tapes will be destroyed once the notes from the interview have been written up.

APPENDIX (AA)

“PROFESSIONALS” Questionnaire

DRE in Mental Health Care – The Qalb Community Engagement and Action Research Project re: South Asian communities as service users

Introduction

This research questionnaire is part of a Community Engagement Project conducted by The Qalb Centre, funded and supported by the National Institute of Mental Health in England (NIMHE) and the University of Lancashire (UCLAN).

The project is part of the Black & Minority Ethnic (BME) Community Engagement programme.

The Qalb Centre is a registered charity that provides community based mental health support services to the Asian and other BME communities in the London Borough of Waltham Forest. The Qalb Centre has been established for nearly 13 years.

Aims of this Project & Questionnaire

The purpose of this questionnaire and project is to explore the extent and patterns of the mental illnesses among the Asian communities; their perception of mental illness and signs and symptoms; their perception of barriers to accessing quality services; and the overall experiences of the mental health services. users. The research will take into consideration culture, religion and languages when considering these issues.

We anticipate that the final outcomes of this research will inform and bring about improvements in the services BME communities receive.

All the community researchers are trained and supported members of the local community. As a professional working in the area we wish to request 40 minutes of your time to kindly answer this questionnaire. We can assure you that any information collected is only for the purpose of the research and will be treated with the utmost **CONFIDENTIALITY**.

.....

CONSENT FORM

This study is being conducted by the Qalb Centre and is about Mental Health issues within the Asian communities.

The aim of the Qalb Centre is to gain better understanding of the situation in Waltham Forest regarding the users / their carers' experiences and their expectation of the services within cultural and religious contexts. A report on the findings will be used to inform policy and also lobby for services for services that you tell us you need.

Please READ the declaration below and ask the researcher to explain any points which are not clear.

I have been requested to participate in this study and voluntarily accept.

I understand:

The aims of the research and I have been free to ask any questions.

My participation is entirely voluntary and I can withdraw at any time.

I do NOT have to answer any questions if I wish not to, but I am encouraged to answer where I can.

Any comments that I make will not be attributed to me. [we have taken 'unless I give consent' out].

All the information provided will be in confidence and it will only be shared amongst those working on the research, EXCEPT if I disclose information which reveals serious harms to me or others (including child abuse) – (This will be dealt with in accordance to The Qalb Centre disclosure procedure)

I am happy for the interview to be taped so that the research team can check what has been said afterwards. I understand that the tapes will be destroyed once the notes from the interview have been written up.

APPENDIX (AAA)

“USERS COMMUNITY” Focus Group

DRE in Mental Health Care – The Qalb Community Engagement and Action Research Project re: South Asian communities as service users

Introduction

This focus group is part of a Community Engagement Project conducted by The Qalb Centre, funded and supported by the National Institute of Mental Health in England (NIMHE) and the University of Lancashire (UCLAN).

The project is part of the Black & Minority Ethnic (BME) Community Engagement programme.

The Qalb Centre is a registered charity that provides community based mental health support services to the Asian and other BME communities in the London Borough of Waltham Forest. The Qalb Centre has been established for nearly 13 years.

Aims of this Project & Focus Group

The purpose of this focus group and project is to explore the extent and patterns of the mental illnesses among the Asian communities; their perception of mental illness and signs and symptoms; their perception of barriers to accessing quality services; and the overall experiences of the mental health services users. The research will take into consideration culture, religion and languages when considering these issues.

We anticipate that the final outcomes of this research will inform and bring about improvements in the services BME communities receive.

All the community researchers are trained and supported members of the local community. As members of this community we wish to request about an hour of your time to kindly take part in this focus group. We can assure you that any information collected is only for the purpose of the research. As a research team we will treat what you say with the utmost confidence unless you give us information which leads us to believe that either you or someone else is at risk of serious harm (including child abuse). However, given that this is a focus group and a number of different people from different who are not part of the research team are also taking part you should understand that we cannot guarantee that nothing that you say will be reported outside of the group by another participant. You should bear this in mind when you decide what to say or disclose.

.....

CONSENT FORM

This study is being conducted by the Qalb Centre and is about Mental Health issues within the Asian communities.

The aim of the Qalb Centre is to gain better understanding of the situation in Waltham Forest regarding the users / their carers' experiences and their expectation of the services within cultural and religious contexts. A report on the findings will be used to inform policy and also lobby for services for services that you tell us you need.

Please READ the declaration below and ask the researcher to explain any points which are not clear..

I have been requested to participate in this study and voluntarily accept.

I understand:

The aims of the research and I have been free to ask any questions.

My participation is entirely voluntary and I can withdraw at any time.

I do NOT have to answer any questions if I wish not to, but I am encouraged to answer where I can.

Any comments that I make will not be attributed to me. [we have taken 'unless I give consent' out].

All the information provided will be in confidence and it will only be shared amongst those working on the research, EXCEPT if I disclose information which reveals serious harms to me or others (including child abuse) – (This will be dealt with in accordance to The Qalb Centre disclosure procedure)

I am happy for the focus group to be taped so that the research team can check what has been said afterwards. I understand that the tapes will be destroyed once the notes from the focus group have been written up.

APPENDIX (B)

DRE steering group

Terms of Reference (Amended)

1. Oversee the development of delivering race equality in Waltham Forest Primary Care Mental health service in collaboration with NELMHT.
2. Implement the National service Framework (2000); Delivering race equality: A framework for action, 2005); Race Relations Amendment Act (2000).
3. Responsible for delivering the local implementation plan for race equality (Local DRE Action Plan, 2005 – 2008)⁷.
4. Provide steering group leadership and support to recruitment and development of community development workers (CDWs).
5. Ensure inter-connectedness between DRE steering group and local BME organisations and coordinate networks with other BME organisations.
6. Review and evaluate progress and action plans. Make recommendations for action and change.
7. Ensure implementation of action arising from the race impact assessment on the planning, commissioning and delivery of primary care mental health service functions.
8. Report to the LIT, NELMHT and DRE Sub-Committee with regular progress updates.

To ensure effective functioning and accountability the steering group will:

9. Ensure that steering group membership is reflective of the range of local perspectives, relating to the delivery of race equality.
10. Meetings will be held bi-monthly for 2 hours.
11. Members of the steering group will act collectively for the interest of delivering race equality.

⁷ Delivering Race Equality, North East London mental Health Services, Action plan 2005- 2008).

12. In the case of a conflict of interest arising within the group, members will declare these to the group and leave the meeting while discussion occurs.

Steering Group Membership

1. Bert McAlpin, Group Manager for Mental health service, LBWF (CHAIR)
2. Althea Bart, BME Alliance
3. Charlene Green, WF Equalities
4. Virginia McGuffie, Primary Care Mental Health Manager (PCT)
5. Sue Merchant, Service Re-design Manager and North sector DRE lead (NELMHT)
6. Nihad Fathi, Community Health Advocate (PCT) Chair of BME Health Consultative Group meetings
7. Baljeet Kaur, Transcultural CPN (NELMHT), Member of NIMHE steering group on CDW Education & Training
8. Representative from Black People's Mental Health Association, BPMHA
9. Dr. Gadhvi Harish, Consultant Psychiatrist (NELMHT)
10. Rosanna Sehmbi, Acute Services Manager, Lead for WF NELMHT Race Equality and Diversity (NELMHT), Representative on NIMHE steering group
11. Najat Elwakili, Primary Care Mental Health Worker, DRE lead for Mental Health in primary care services (PCT)
12. Yasmin Choudhary; Imran Aziz Mirza (UCLAN); Qadir Bakhsh, QALB Mental Health Centre
13. Natalie Sarjveladze-Weeks, Refugee Psychology service (NELMHT)
14. Arnold Zulu, African Forum
15. Jacqui Van Rossum, Borough Director Waltham Forest (NELMHT)
16. Malcolm Couldridge, Capital Volunteering Mental Health co-ordinator, CREST

APPENDIX (C)

**Delivering race equality
North East London Mental Health Services
Waltham Forest DRE sub group to LIT**

Meeting to be held on Thursday 27th July 2006,
2 – 4pm
Kirkdale House, Room 1 (4th Floor)

AGENDA

1.	Apologies for absence		
2.	Introductions <ul style="list-style-type: none">• New chairing arrangement• Welcome to new members		
3.	For Information <ul style="list-style-type: none">• Minutes of the 14th June DRE WF sub group meeting		Enc 1
4.	Draft 2 of DRE action plan revised (2006/7) <ul style="list-style-type: none">• Finalise draft and performance measures		Enc 2
5.	Ethnicity monitoring <ul style="list-style-type: none">• Snapshot of ethnic uptake from key community services in WF• Report from NELMHT on ethnicity coding and figures for acute mental health services		Enc 3
6.	Count Me in Census Summary report		
7.	CDW local work programme (Draft)		BK/RS

8.	Community engagement project <ul style="list-style-type: none"> • Progress review on Qalb project (Imran/ Qadir) 		
9.	Any Other Business		

**Delivering Race Equality
North East London Mental Health Services
Waltham Forest DRE sub group to LIT**

Minutes for meeting held on 15th June 2006

Present

Nick McNulty (Chair, PCT), Rosanna Sehmbi (NELMHT), Qadir Bakhsh (QALB), Imran Mirza (University of Central Lancashire), Arnold Zulu (BME Alliance), Kelvin Goodwin (BPMHC), Virginia McGuffie (PCT)

1. Apologies

Natalie Sarjveladze-Weeks (NELMHT)
Bert McAlpin (LBWF)
Nihad Fathi (PCT)
Najat Elwakili (PCT)

2. Welcome and Introduction

3. Minutes

- 2.1 Pick up EIP with RS. For next agenda
- 2.2 Count Me In Census – not available. For next agenda

4. Delivering Race Equality Action Plan

4.1 Page 5 of DRE Action Plan

- Need a baseline for psychological therapies. Need to identify people taking the lead on this. Once baseline is established it needs to be agreed by DRE group
- Need to specify target number of service users identified
- Need to specify target number of attendance
- Need a concrete measure: for example, do talking therapies reduce admission: EIP evidence: assessing trends; work around voluntary sector impact on admissions: is there any local evidence?; studies on whether therapists make a difference

4.2 Action Plan needs to

- include details about Community Engagement Project and QALB research

- say how people will report back , who they will report to, reporting to the LIT

5. Ethnicity Monitoring

- **5.1** Ethic monitoring pye charts from PCT and NELMHT
- OK but this information needs to be put in a table with the ability to spot any discrepancy in %s
- **5.2 Solutions**
- Clients are reluctant to fill in ethnic monitoring on self-referral form
- PCPPs are being asked to do this
- Need 100% target
- **5.3 NELMHT**
- Breakdown of inpatient data April 05 to March 06
- Better recording in quarter 3 – 69%
- Awaiting quarter 4
- Recording needs to be increased by December
- Data will be broken down into individual care units – at present certain care units have predominantly one ethnic staffing
- Breakdown of staff group – this needs to be compared with population of WF
- Number of BME staff in top jobs
- How to get a better ethnic mix

6. CDW local work programme

- Job Description revamped and with JVR
- A4C to rebadge post
- NM asked for this process to be speeded up so BK can be in post by September
- Areas of work for CDW to be prioritised.
- NE will provide details of BME groups in WF

7. Community Engagement Project (CEP)

- 7.1** Progress Report presented by Imran Mirza and Qadir Bakhsh which included
- A list of tasks for project
- Need for support from DRE group
- Not an academic piece of work – all perspectives will be looked at and linked to DRE Action Plan
- Training days organised: 2 sessions mental health; 3 methodology
- Produce draft for research tools – feedback
- Formulated recommendations – support from DRE group
- Links around local/national strategies
- Link in with Capital Volunteering
- Entry for academic training
- Draft report - January, 2007
- Completed report - March 2007

- Assignments – end October/November
- Link with each of the Community Engagement Projects
- **LAUNCH Thursday, 20th July 10 -1 including lunch**

7.2. Next meeting

- Comments on CEP progress report
- CEP to produce on-going report
- Links to overall DRE

8. Future Lead and Chair Arrangements

- Bert McAlpin proposed for future lead

APPENDIX (D)

Link between The Qalb Centre Community Engagement Programme and the delivery of Race Equality in Waltham Mental Health Services

(A) Introduction and Context

The local action plan for delivering race equality in Waltham Forest mental health services (2005 – 2008) is based on the 3 building blocks proposed within DRE (DoH, 2005):

- (I) **More appropriate and responsive services** - achieved through action to develop organisations and the workforce, to improve clinical services and to improve services for specific groups, such as older people, asylum seekers, and refugees, *BME groups*, and children. *Work force development*: BME community input into service planning and input for the induction and training for new primary care staff
- (II) **Community engagement** - delivered through healthier communities and by action to engage communities in planning services and accessing services, supported by 500 new Community Development Workers. *CDW key functions include change agent, service developer, capacity -builder, and access facilitator to services.*

- (III) **Better information** - from improved monitoring of ethnicity, better dissemination of information and good practice, and by improving knowledge about effective services. This includes a new yearly census of ethnicity of mental health patients.

{ Input-Output-Outcome }

(B) The Qalb Centre Community Engagement Project

(i) Aim of the Community Engagement Project

The aim of the project is to explore what mental health services are available for the Black and minority ethnic communities in Waltham Forest, and comment on their appropriateness with regard to faiths, cultures and diversity generally, and suggest how they could be improved, addressing diversity implications.

(ii) Objectives

- (a) To highlight the service experiences of BME mental health service users and their carers'.
- (b) In the light of (a) above, to make recommendations that will contribute to the delivery of better mental health services for BME communities in line with *Delivering Race Equality in Mental Health Care*.
- (c) To recommend action plans specifically *Delivering Race Equality*, designed to deliver on three key aims:
- Equality of access
 - Equality of Experience progress.
 - Equality of outcomes
- (d) To work closely with key stakeholders in Focused Implementation Sites towards making *Delivering Race Equality* happen on the ground, by various means.
- (e) To articulate new and innovative ideas and assess efforts and strategies developed by various Mental health service providers about how to go about delivering some of the outcome envisaged in DRE. (See Section (VI) below)
- (f) To empower and facilitate mental health service users and their carers (as workers /researchers and volunteers) in engaging with mental health service providers to voice their needs in shaping the mental services provided for them which are appropriate to their needs.

(iii) Research Focus and Methodology

(1) CORE INFORMATION

Age, gender, ethnicity, sexuality, religious, socioeconomic status (specified by the University)

(2) PERSONAL EXPERIENCES

Their perception of mental illness and signs and symptoms

Explore extent and patterns of their illnesses

Quality of experiences in accessing services,

Perception of barriers to accessing quality services

(3) PERCEPTION OF CULTURALLY COMPETENT SERVICES and EXPERIENCES

Their views about culturally competent services

What constitutes culturally competent services?

Whether they have received any cultural competent service

(4) 2010 VISION – SOME ASPECTS

Their specific fears as barriers

Satisfaction Level

Perception of violence, seclusion, and therapies

(C) Link between the local DRE action plan and CEP

The local Action Plan for DRE is very comprehensive addressing all the three building blocks referred to above, including the 12 characteristics of 2010 vision and requirements of the Race Relations (Amendment) Act, 2000, besides other drivers.

The CEP is essentially meant to explore the ‘Community Engagement’ Building Block with a view to capture experiences of BME communities in the Mental Health Services Provision viz-a-viz cultural competency and perception of and experiences exclusion etc. (Please see the Research Focus above). The CEP will no doubt relate to the two other building blocks to see effectiveness of efforts and document outcome measures, if possible.

Any information gathered during the process will be fed into the accomplishment of two other building blocks and the development of the work programme of the Community Development Worker(s).

The CEP will be able to identify a number of key community stakeholders, including users and carers or key workers within the voluntary sector in order to contribute to the achievement of DRE goals.

As part of the programme a detailed report will be produced with conclusions and recommendations for ensuing work of the DRE steering committee and peculiarly sustaining community engagement.

Throughout the research/engagement process guidance and support will be sought from the local DRE Steering Committee and the focus will be adjusted, if needed, to contribute to their action plan for DRE, eg. our research design, research tools will be approved by them and the sample will be used recommended by them, if different from what is being proposed.

(D) Community based Research

The CEP is being developed and delivered with the community action research spirit, the kind of role envisaged for the Community Development Worker –

Philosophically it is recognised that citizen participation in social policy affairs has educational effects on the participating citizens. Contrary to a researcher looking in from the outside, instead community/action researchers are deployed who are part of the process of social change, representing the community values and aspirations and championing those ideals, with the support and help of the community.

They tend to learn from the community at large, consolidate and feedback to the community for sharing widely in order to internalize and inculcate ownership.

Action and community based research is not only empirical and experimental but it is diagnostic and participatory. The community/action researcher is:

- 1 an agent of social change,
- 2 a broker at times,
- 3 both a researcher and the researched
- 4 involved in the ensuing action programme and is a beneficiary as a community member
- 5 a facilitator and a resource
- 6 part of the decision making machinery
- 7 sympathetic and empathetic
- 8 gives information and helps make decisions
- 9 supplies knowledge and understanding in support of change
- 10 makes the research findings as part of shared experience
- 11 believes in community participation, development and engagement
- 12 has insightful understanding

The mental health service users thus involved in the CEP will perform the above role and will have the authority to question whether the process will lead to the desired outcome, envisaged by DRE in this case. Therefore as part of process key stakeholders with responsibility and resources will be quizzed to ascertain their shared vision of achieving some of the outcomes targets.

(E) A Seminar Report

On 27th of July, 2000 a seminar was held by the Qalb Centre to launch the CEP and to publicise the DRE to different stakeholders. A detailed report, giving various perspectives including those of the communities (service users) and the voluntary sector has been prepared.. Around 50 delegates participated in the seminar and some of their views and concerns, will be included in the final report – and hopefully will be fed into revising the local DRE Action Plan.

Qadir Bakhsh
30.8.2006

7. REFERENCES & BIBLIOGRAPHY

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