

**COMMUNITY ENGAGEMENT PROJECT: the NIMHE Mental Health Programme**

**A BLACK AND ASIAN MENTAL HEALTH RESEARCH PROJECT IN DERBY  
FOCUSSING ON THE EXPERIENCES OF 18+ BLACK AND SOUTH ASIAN  
SERVICE USERS AND CARERS IN THE DERBY CITY AREA.**

On behalf of  
**DERBY MILLENIUM NETWORK**  
MAY 2007



Funded by the NIMHE, Derbyshire County Primary Care Trust and Derby City Primary Care Trust  
managed and supported by  
The Centre for Ethnicity and Health, University of Central Lancashire.



**A statement from the Chair  
Delivering Race Equality Steering Group – Derby and Derbyshire**

I was pleased to be asked to add my comments to this report. As chair of the Derbyshire Delivering Race Equality in mental health care steering group, I have been working with DMN for the past 4 years on the DRE programme.

There is significant evidence available about the poor experience that people from BME communities have of mental health services. However, the importance of up to date local information should not be underestimated.

The researchers have presented us not only with the evidence of individuals experiences, but also with clear and practical recommendations that will add strength and validity to our work programme and support the case for change. I would like to thank them for their hard work and express the hope that they may continue their involvement in some way.

Ruth Sargent  
**Head of Mental Health Commissioning  
Derby and Derbyshire PCTs**

Published by Derby Millennium Network

Editing, pagination, typesetting, format, proofing and layout carried out by:  
Bimmy Rai (CEO) and Jayesh Jani, Health and Social Care Partnership Officer (HASCPO)

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**A BLACK AND ASIAN MENTAL HEALTH RESEARCH PROJECT IN  
DERBY FOCUSING ON THE EXPERIENCES OF 18+ BLACK AND  
SOUTH ASIAN SERVICE USERS AND CARERS IN  
THE DERBY CITY AREA**

**Carried out by the Derby Millennium Network's  
Community Engagement Research Team**

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In association with  
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Special thanks to  
Bahar Ali Kazmi  
External Research Collaborator

Note: The views expressed in this report are those of the research team that undertook the work, and are not necessarily those of the Centre for Ethnicity and Health at the University of Central Lancashire

## **Joint Foreword by Chair and Chief Executive of Derby Millennium Network**

Derby Millennium Network (DMN) established in 1999, is the key black-led strategic umbrella and development organisation championing the issues affecting BME communities. DMN is committed to developing structures that empower and enable those who are traditionally excluded from power and the decision-making processes.

We seek to develop the resources, power, skills, knowledge and experiences of Black and Minority Ethnic voluntary and community groups and individuals thus enabling them to undertake initiatives which combat social, economic, political and environmental problems.

Since its inception, DMN has:

- Established a broad based membership of Black and Minority Ethnic (BME) Culturally Diverse (BCD) voluntary and community organisations and has created a package of benefit for members.
- Has identified and promoted the BME voluntary sector agenda by ensuring that policy makers, capacity building agencies, local government and other relevant bodies are made aware of and act on the concerns of the sector.
- Have developed networks that have enabled the exchange of skills, information and shared approaches to tackling issues facing Black and Minority Ethnic communities.

This Community Engagement Project report is the latest of a series of research initiatives that the DMN has carried out over the years. This research project is also a key deliverable of the Delivering Race Equality (DRE) in Mental Health Care. This is a five year action plan for achieving equality and tackling discrimination in mental health services in England.

The findings and recommendations from this programme are based on community engagement with particular focus on the experiences of Black and South Asian Service users and Carers in the City of Derby.

DMN is committed to ensuring that the overall learning's, findings, and recommendations will:

1. Help to build the capacity in the black and minority ethnic voluntary community sector by leveraging in both financial resources to the sector in order to increase the awareness and ownership from the BME communities and organisations.
2. Encourage the engagement of Black and minority ethnic communities in the commissioning process of mental health services in Derbyshire. Continue to involve Black and Minority Ethnic Culturally Diverse voluntary and community organisations in identifying their needs and work with statutory service providers in the design and delivery of more appropriate services that effective and responsive to these communities.
3. Continue to foster greater community participation in, and ownership of, mental health services by allowing local populations to influence the way these services are planned and delivered.

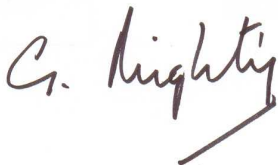
## Joint Foreword by Chair and Chief Executive of Derby Millennium Network

4. Contribute to development of the Community Development Workers managed by DMN and those by our partners across Derbyshire.
5. Contribute towards enhancing good practice amongst mental health practitioners and professionals.

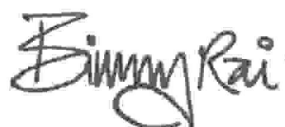
We would like to thank the following without whom this important research project would not have materialised:

- The National Institute for Mental Health in England (NIMHE - responsible for supporting the implementation of positive change in mental health and mental health services), The Care Services Improvement Partnership (CSIP) - East Midlands Development Centre, Derbyshire County Primary Care Trust and Derby City Primary Care Trust for funding this project
- The Centre of Ethnicity at the University of Central Lancashire for their support and assistance in the management of the project.
- All of the DMN staff members, volunteers, community researchers and associates for their contribution in ensuring the successful outcome of the project.

We hope that the report and the findings will enable us to become the 'change-agent' in implementing the recommendations with our relevant stakeholders to help shape future service delivery to the BME communities across Derby and Derbyshire.

A handwritten signature in black ink that reads "G. Mighty". The signature is written in a cursive style with a long horizontal stroke at the end.

**Mr. George Mighty, MBE, JP**  
**Chairman**  
**Board of Directors**

A handwritten signature in black ink that reads "Bimmy Rai". The signature is written in a cursive style.

**Ms. Bimmy Rai**  
**Chief Executive**

## ACKNOWLEDGEMENTS

The Black and Asian Mental Health Community Engagement Research Project was funded by NIMHE – East Midlands Development Centre (CSIP), Centre for Ethnicity and Health at the University of Central Lancashire (UCLAN), Derbyshire County and City Primary Care Trusts. The research project was supported by a Steering Group which comprised of representation from Derbyshire Mental Health Services Trust, Derbyshire Mind, Rethink, Karma Nirvana, Derby African Caribbean Mental Health Association (DACHMA - a subsidiary of the Hadhari Project and Elderly Day Care Centre), Asian Women's Mental Health Group, Derby Refuge, Derbyshire Carers Association, The Elms Clinic and the University of Derby's School of Health, Education and Social Science.

Derby Millennium Network would like to thank the funders and partners, all of the community engagement research team, the research steering group members, DMN staff team, volunteers and all the services users who supported and participated in this research project.

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## **Section 1: Executive Summary**

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### **Making Mental Health Services Culturally Competent, Voices of BME Service users and Carers**

There has been some improvement in the cultural competence of mental health services over the last five years. The evidence however suggests that both Service users and carers are dissatisfied with main stream mental health services.

In this study, we have made efforts to identify gaps in mental health services for Black and Minority Ethnic (BME), Black Culturally Diverse (BCD), and dual heritage Service users and carers. In so doing we have focused on the experiences of 23 Service users and 15 carers aged 18 and over.

The experiences of BME Service users and carers who participated in this research suggest Service users and service providers have different perspectives in understanding of the scope of cultural needs and they differ significantly on the process of treatment and recovery.

Cultural and communication gaps have been compromising the cultural competences of the mental health services in Derby. We believe that the quality and appropriateness of mental health services in Derby City can be improved.

#### ***Regarding this we suggest the following steps:***

1. Establish a policy forum, involving all the stakeholders including Service users and carers that work on the cultural competence of the mental health services in Derby City focusing on the scope of the cultural needs of the Service users and culturally responsive treatment and recovery process. The forum should deliver a uniform and agreed policy guideline for the service providers in Derby City.
2. Review the cultural competences of GPs, and other staff members of mental health services.
3. Encourage GPs to take into account both the cultural background of Service users and their individual histories and their views about the process of treatment.
4. Increase the involvement of families and carers in the treatment and recovery process.
5. Increase access to talking and alternative therapies, making them available as standard in mainstream mental health services.
6. Information about treatment should be made widely available at community level in appropriate languages.
7. Find ways of delivering mental health services at community level.

***Regarding future Community Engagement Projects we suggest the following steps:***

1. Specialist research analysis and co-ordination support needs to be provided on a full-time basis to support this type of project and the funding streams need to be recognised in order that appropriate support exists with this type of project in order to meet the development needs of the community researchers throughout the duration of the project. This support must not be tagged on the back of existing mental health posts as this is a specialist area of work and requires levering in that specialist skill.
2. The Steering Group members should have more clearly defined roles and an implementation structure.
3. There needs to be a clearer framework about what the research team/UCLAN support worker relationship will involve.
4. The time commitment asked of community researchers needs to be realistic in line with the scope and scale of the project and be highlighted at the start.

## Section 2: Background and Context

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### Context for the Mental Health Community Engagement Programme (CEP)

*Delivering Race Equality (DRE) in Mental Health care\** is a five year action plan for achieving equality and tackling discrimination in mental health services in England. It also outlines the Government response to the recommendations made by the inquiry into the death of David Bennett for all people of Black and minority ethnic status, including those of Irish or Mediterranean origin and east European migrants. The action plan has the potential to improve the care for any group affected by disparity in health and healthcare, including Black and minority ethnic older people, children and adolescents, refugees and asylum seekers.

Equality in mental health services is not a new requirement. Many of the actions described in DRE have their roots in existing legislation, guidance or initiatives. Many are to be taken at national level, by the Government or other bodies. DRE pulls them all together, sets them in a mental health context, and adds the key, focused activity that is needed now to ensure rapid delivery.

Specifically *Delivering Race Equality* is designed to deliver on three key aims:

1. Equality of access
2. Equality of Experience progress.
3. Equality of outcomes

\* You can download the whole document from <http://www.dh.gov.uk/PublicationsAndStatistics>

### Building blocks

The Delivering Race Equality programme of change is founded on three building blocks;

- **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, and children.
- **community engagement** - delivered through healthier communities and by action to engage communities in planning services, supported by 500 new Community Development Workers.
- **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.

### The Five Year Vision

The five year vision for DRE is that by 2010 mental health services should be characterised by:

- less fear of mental health services among Black and minority ethnic communities and Service users
- increased satisfaction with services

- 
- a reduction in the rate of admission of people from Black and minority ethnic communities to psychiatric inpatient units
  - a reduction in the disproportionate rates of compulsory detention of Black and minority ethnic Service users in inpatient units
  - fewer violent incidents that are secondary to inadequate treatment of mental illness
  - a reduction in the use of seclusion in Black and minority ethnic groups
  - the prevention of deaths in mental health services following physical intervention
  - more Black and minority ethnic Service users reaching self-reported states of recovery
  - a reduction in the ethnic disparities found in prison populations
  - a more balanced range of effective therapies, such as peer support services and psychotherapeutic and counselling treatments, as well as pharmacological interventions that are culturally appropriate and effective
  - a more active role for Black and minority ethnic communities and Black and minority ethnic Service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services
  - a workforce and organisation capable of delivering appropriate and responsive mental health services to Black and minority ethnic communities

### Steps in Delivering Race Equality

The main elements of the DRE action plan include:

- PCTs providing more responsive services based on the needs of the local population, helped by local demographic data;
- NHS trusts being assessed by the Healthcare Commission on their performance in challenging discrimination and providing equality of access;
- a new commitment to reduce the disproportionate rates of compulsory detention of black and ethnic minority mental health patients and preventing deaths in mental health services following physical intervention;
- creating a work force that has the knowledge and skills to deliver equitable care to black and minority ethnic populations with support from the Royal College of Psychiatrists and better race equality training;
- an important role for the non statutory sector, supported by a £2 million national community engagement scheme to help PCTs identify Black and minority ethnic voluntary and community organisations that can advise them, and, in some cases act as partners in delivering services. PCTs will be supported by 500 new community development workers;
- NHS Direct providing a national interpretation and translation service and PCTs providing directories of NHS and social services targeted at Black and minority ethnic people; and

- working with the Home Office and police to improve local liaison and the National Patient Safety Agency (NPSA) to reform the process-of independent inquiries and issue guidance on creating safer-environments on acute psychiatric wards.
- new focused implementation sites where Strategic Health Authorities (SHAs) and organisations will work together, on a local level, to drive change in mental health services for Black and minority ethnic people and develop best practice.

There is a need for an effective framework that can deliver better and more culturally appropriate, clinically effective and recovery orientated care for Black and minority ethnic communities, as well as demonstrate how the different initiatives will produce the improvements needed. Many different organisations will need to be involved in delivering the programme, reflecting the complex nature of mental health service development.

### **Focused Implementation Sites (FIS)**

Seventeen sites across the country will pioneer best practice in eliminating discrimination in mental health care. The sites will work to drive the implementation of Delivering Race Equality in Mental Health Care They will help identify and spread best practice by developing the evidence base and facilitating the roll out of the DRE Action Plan demonstrating from the outset that change can be achieved, Implementation of the plan should have begun everywhere, but these sites will act as 'hothouses of reform' to demonstrate Government's seriousness about following through the commitments made in Delivering Race Equality in mental health care. These sites will be known as Focused Implementation Sites (FIS).

The successful SHAs are: Northumberland, Tyne & Wear, West Yorkshire, County Durham & Tees Valley, South Yorkshire, Leicestershire, Northamptonshire & Rutland, Trent, Bedfordshire & Hertfordshire, South East London, North East London, North Central London, North West London, Hampshire & Isle of Wight, Surrey & Sussex, South West Peninsula, Dorset & Somerset, Birmingham & the Black Country and Greater Manchester.

Focused Implementation Sites are the next steps towards making Delivering Race Equality happen on the ground and will act as a valuable source of best practice and support.

In particular the sites will:-

- demonstrate that a whole systems approach improves mental health services for Black and minority ethnic groups, drawing on and adapting the 'collaborative' approach used successfully in other areas of health care;
- provide leadership and raise the profile of the Black and minority ethnic programme;
- develop strategic partnerships between key organisations to lever investment and build capacity;
- build capacity and intelligence that will facilitate further change;
- directly and quickly improve mental health services for Black and minority ethnic populations.

New regional race equality leads will provide local leadership for the DH and NIMHE Black and minority ethnic programmes, including this action plan. They will develop and implement race equality within NIMHE and regional and local services, as well as providing leadership and mentoring to community development workers in their areas.

## Section 3: UCLAN Model of Community Engagement

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### The University of Central Lancashire (UCLAN) and 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 they are used inter-changeably to mean the same thing. Sometimes the same word or phrase is used by different people in the same meeting to mean different things. The Centre for Ethnicity and Health has a very specific notion of Community Engagement, and this paper is an attempt to describe it. The Centre's Model of Community Engagement has evolved as a result of its involvement in a number of projects over the years. Perhaps the most important milestone however came in November 2000, when the Department of Health awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire 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 Department of Health had two key things in view when it commissioned the work; first, the Department of Health wanted a number of reports to be produced that would highlight the mental health 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 Department of Health had wanted was a needs assessment and a 'glossy report', they could have directly commissioned a number of researchers who could have gone into local Black and minority ethnic communities, talked to them about their needs, written up a report, and produced yet another set of reports that potentially do not have any long term impact. This scheme was different however.

The Department of Health 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 mental health or anything about undertaking a needs assessment at the start of the project; what they would have is 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 six month process to learn about drug related issues and about how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity & 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 mental health, 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. 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 or domains of work. These include:

- Substance Misuse
- The Criminal Justice System
- Sexual Health
- Mental Health
- Regeneration
- Higher Education
- Asylum

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 people
- Women
- White deprived communities
- Rural communities

In addition to the Department of Health, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, The National Institute for Mental Health in England, the Greater London Authority and Aim higher.

### **The Key Ingredients**

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 host community organisations. This may be an existing community group, but it might also be necessary to set a real or virtual group up where one does not exist already. The key thing is that this host community organisation should have good links to the target community (whoever this is) such that it is able to recruit a number of people from the target community take part in the project and to do the work. It is important that the host community organisation is able to provide a co-ordination and infrastructure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day to day activities that will be undertaken once the project is underway.

## Section 3: UCLAN Model of Community Engagement

continued

One of the first tasks that this host community organisation undertakes will be to recruit a number of people from the target community to work on the project.

A host community organisation	With good links to the target community.	To provide basic infra-structure support for the Project (recruit and co-ordinate Project Team; provide office space, phones and computers; look after the finances).	To recruit a number of people from the target community to do the work.
A Task	Time limited Meaningful Manageable	A piece of research into key needs/gaps/issues for the community	Learning and development of key individuals; access hard to reach groups; raise awareness and debate; community ownership.
Support	Financial (typically up to £20,000)	Training and workshops; on-going support and guidance; Personal Tutor.	Statutory partnerships; Steering Groups; sustainability.

The second key ingredient is the task that the community is to be engaged in. According to the Centre for Ethnicity and Health model, this must be something that is meaningful, time-bound and manageable. Nearly all of the community engagement projects that we have run have involved communities in undertaking a piece of research or a consultation exercise within their own communities. Sometimes we have been met with an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme that we ran on behalf of the Department of Health, the process (i.e. of getting ordinary people involved in doing the work) is as important, if not more important, than the report that they produce at the end of the day.

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. We do not expect community groups to become involved for nothing. We would expect that the bulk of this money would be used to pay people from the target community as community researchers. We then allocate a named member of staff from our Community Engagement Team 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 through the project.

We also provide a package of training – typically in the form of a series of accredited workshops. 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 pull together a steering group for the project.

## Section 3: UCLAN Model of Community Engagement

continued

The steering group is an essential element of the project: without one, it is difficult to see who the community are engaging with and it is unlikely that anything out of the project will be sustained in the longer term. The group will be doing a needs assessment or a consultation exercise, but for what purpose? It is the role of the steering group to ensure that the work that the group undertakes sits with local priorities and strategies, and that there is a mechanism for picking up the findings and recommendations that the group may make. It is also their role to help to pick up the key individuals who are developed through the project process to help them to take their 'next steps'.

### The Community Engagement Team

The Community Engagement Team comprises of 25 members of staff. They work across a range of Community Engagement areas of specialism, within a tight regional framework.

National Programme Directors			
Northern Team	Midlands Team	Southern Team	
Senior Support Worker	Senior Support Worker	Senior Support Worker	
			Drug Interventions Programme
			Regeneration
			Mental Health
Teaching And Learning Team			
Administration Team			
Communications Officer			

### Programme Outcomes

Each group involved in any of our Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community that it consulted with. The qualitative themes that emerge from the reports are often very powerful, particularly when taken together with other reports produced by groups involved in the same programme. Such information is key to commissioning and planning services for diverse and 'hard to reach' communities. Often new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

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. Since 2000 over 200 community groups have taken part in one or other of the Centre for Ethnicity and Health's Community Engagement Work Programmes.

## **Section 4: The Research Project**

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### **Research Title: Cultural competence in the Mental Health Services in the Derby City Area: The experiences of 18+ Black and South Asian Service users and carers.**

#### **Research Objectives:**

- To identify gaps in service provision for adults
- To make recommendations for cultural competence in the Mental Health Services in the Derby City Area.

This research is underpinned by the following DRE and National priorities:

#### **Delivering Race Equality (DRE):**

- Less fear of mental health care and services among BME communities and BME Service users;
- Increased satisfaction with services;
- A reduction in the disproportionate rate of admission of people from BME communities to psychiatric inpatient units;
- A more balanced range for effective therapies such as peer support services, psychotherapeutic and counselling treatments, as well as pharmacological interventions that are culturally appropriate and effective;
- A more active role for BME communities and BME Service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services; and
- A workforce and organisation capable of delivering appropriate and responsive mental health services to BME communities.

#### **The National Priorities:**

- The development of more appropriate and responsive services for the black and minority ethnic communities by statutory service providers.
- The development of a health workforce capable of working with and treating different communities.
- Better engagement of black and minority ethnic groups in shaping mental health services and supporting innovative, community informed services.
- Better collection and more effective use of information to assess and target service developments.

## Section 4: The Research Project

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### The Research Team

Six researchers with the support of wide range of organisations have conducted this research. All of them have experienced mental health services either as Service users or as carers, or working within the mental health services and they are a part of the community which participated in the research. The research team consisted of both male and female, from diverse backgrounds, (African-Caribbean, South Asian, African, Pakistani and Black British), of various ages, from various faith groups and spoke various languages. The team members were;

Muhammad Abdullah Shahjan – 31, a community researcher. A devoted father and family man, Abdullah enjoys helping out in the local community. Abdullah has read at various universities and continues to enjoy learning. Presently Abdullah enjoys working in the NHS as a Faith Adviser and Hospital Chaplain and presents a weekly health show on a local community radio station.

Aliyah Muhammad – 34, a community activist and a researcher. A dedicated mother and devoted wife, Aliyah takes great pleasure in the arts, and has a flare for needle work and crafts. Aliyah has supported and campaigned, research initiatives internationally and has worked at Howard University in Washington DC. Aliyah's experience in research skills and delivery has assisted in her understanding of the challenges and the complexities that surround research in mental health. Aliyah has a keen interest in the dynamism of the community and has actively engaged in roles in social care and social reform.

Azra Bi – 35, a research volunteer. Azra is an active member of the community. As well as working on this project she works for the Primary Care Trust as a community interpreter and is also a student studying towards a foundation degree in Community Regeneration and Development at the University of Derby. Azra has previous experience of mental health services and understands the stigma and issues surrounding mental illness.

Herbert Mukarakate – is in his fifties, and a research volunteer. Herbert has over two decades of insurance expertise. Herbert enjoys working with others and believes in commitment and unity. The opportunity to work as a group to discover mental health issues in the community is an exciting task and he recognises the challenges associated with people from the community. Herbert's desire to engage in mental health research in the community has encouraged him to be an agent and a mechanism for a more resourceful future.

Lee Pinkerton - 38 years old, married with two children. Lee's employment background is in the media working for a number of years as a contributor to the Voice newspaper amongst others whilst living in London. After moving back to Derby three years ago and a career change, his interest in Mental Health was sparked by experiences in his extended family. He is currently studying Psychology at Nottingham Trent University and is hoping to pursue a career as a Clinical Psychologist

Rashpal Rai - 40 years old and a loving mother and wife, Rashpal enjoys the company of children and supports a local a nursery group. Rashpal has over a decade of experience in human resources and has more recently returned to work after some years of absence, to involve herself in a substantial exploration of mental health. Rashpal continues to advance in her learning and self reliance. Rashpal has engaged in the community to aid and affirm the needs so often under represented or misunderstood by our communities.

### Working together as researchers

All the members of research team had experience of Mental Health services; there was a mixture of Service users and people working in Services within the group. This provided a varied base of experience and views on services. They were from various ethnic groups: Asian Bangladeshi, Asian Pakistani, Asian Indian, Black African, Black Caribbean, with a corresponding range of languages spoken. The team arranged to work 5 hours per week in one session on Thursday afternoons. In retrospect this was not enough time and perhaps 2 sessions per week would have kept the momentum and motivation of the team going.

The researchers had various skill and education levels. Not all the researchers were confident on computers which caused communication challenges as email was the most used means of communication. This also resulted in those researchers having limited inclusion in the data input and analysis stage of the project. The research team began as 10 with support from volunteers however this reduced to 6 active researchers and 1 volunteer.

The research team bonded quite quickly and built respectful relationships with each other, communication within the team was relaxed and at times jovial. As there was a large number of us especially at the onset of the project, decision making and completing work held challenges. We sometimes found it difficult to stay on point, as we all had differing views and opinions and could take a long time debating points, especially if we were lacking expert guidance.

We realise that due to the size and nature of the research team, closer supervision was required with more definition of roles and responsibilities. The implications of the team having differing capabilities could affect the efficiency of the team at times. When unplanned events or absences occurred the team required support to refocus on the tasks and continue the momentum and motivation. Team members required support and time off from time to time, especially the Service users and those with ongoing mental health issues. Some support was required of the CDW due to the impact of interviews on researchers. We were listening to and inputting stories which were quite sad and we were helped through the effects of these by the CDW and by communicating feelings with other team members.

Research skills were increased for some researchers. Most of the team had little or no awareness of research prior to the project. 5 of the research team completed the University of Central Lancashire research qualification during the project. 2 of the researchers also undertook some computer training in order to increase their knowledge of the technology used.

And all the team increased their knowledge of mental health issues and of the services, especially within Derby City. Communication and team working skills were increased as did awareness of local communities and the resources available to them. Most researchers felt they learned a lot during the project - about research and about themselves, and they gained new skills. This research falls in the category of qualitative inquiry because it focuses on the stories of experiences of the Service users and carers. However it is not a straight forward qualitative research; it is led and conducted by the Service users, carers and those community members who experienced the cultural performance of the mental health services in Derby City. Crucially it is simultaneously an effort to conduct a high quality empirical research and to learn how to do it. It is an unfolding rather than a predefined methodological endeavour. In this section, our aim is to tell the tale of conducting this research.

## **Section 5: Research Methods and Process**

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### **5.1 The Training**

UCLAN (The University of Central Lancashire) organised 7 workshops – 2 covering a basic understanding of Mental Health and 5 on the research process.

The first 5 workshops took place in July and August 2006 these covered mental health and the start of the research process – deciding on a methodology, how to plan and execute focus groups, structured interviews and questionnaires. The last 2 workshops were in November 2006 and covered data analysis and reports.

These workshops provided an opportunity for team building in the early stages of the project and set the basis for our team working. They also enabled the researchers to meet other project teams from the Midlands which gave us perspective of our research within a national framework. The workshops also provided us a great opportunity to learn about the other projects and to see what methods they used and to consult with them.

Even though the workshops helped us to define the analytical parameters of the research our experiences revealed that we needed further elaboration regarding data structuring and analysis.

The CDW based at DMN organised and provided training to the research team in the following areas:

- An overview of the Mental Health System and Drugs and mental health – Clem Nichols, 17<sup>th</sup> August 06.
- The WRAP (Wellness Recovery Action Plan) seminar, 7<sup>th</sup> & 8<sup>th</sup> September 06.
- The NHS and related organisations, commissioning of services, monitoring/performance management, the Local Mental Health Implementation Team. Ruth Sargent, 21<sup>st</sup> September 06.
- Personality Disorder Awareness Training, Mike O’Sullivan, Derbyshire Mental Health Services NHS Trust, Kingsway Hospital, 26<sup>th</sup> October 06.
- Mental Capacity Act Regional Launch, 18<sup>th</sup> December 06.

This training was useful in giving the researchers some background knowledge on the services in Derby and on mental illnesses. The training also provided an opportunity to meet others involved in the field of Mental Health and have discussions and broaden our knowledge. The CDW also provided ongoing training in response to our queries.

### **5.2 Defining the Focus**

The first step in the process was to decide a research focus. This was done in the UCLAN workshops in a group exercise including all the researchers. The research focus was narrowed to the BME groups represented in the research team (Black and South Asian). The team felt that when discussing the sensitive subject of their mental health, they would be better able to encourage confidence and rapport with respondents of the same ethnic background and in some cases of the same gender.

In addition to this, the research team worked out the policy relevance of its research. It established that the research must meet the national priorities.

### 5.3 Research Tools

The next stage was to complete the university's ethics pro forma. This required the researchers to be clear on the method they would deploy to carry out the research and to prepare for the risks involved in the process and to minimise those risks where possible.

The exercise began in August and completed in October 2006. During this period, the research team produced a complete set of research tools.

#### August 2006

- Flyer publicising the project and requesting volunteers to be interviewed.
- Information sheets to read or give out to respondents before interviews and focus groups.
- The first draft of the interview questionnaire including questions for carers and Service users.
- A project timeline, showing upcoming events and tasks and responsibilities.

#### September 2006

- The questions for each focus group: carers, professionals, Service users – mixed gender, and Service users – females only.
- Interview questionnaire revised
- Ethics pro forma revised after feedback from UCLAN

#### October 2006

- Revised Interview questionnaire
- Revised Ethics pro forma
- Revised all Focus group questions

#### November 2006

- Revised Interview questionnaire, final draft approved on 23 November 2006.
- Health professional's focus group conducted and transcript created of session from recordings.
- Assignments completed for UCLAN qualification.

#### December 2006

- Assignments completed for UCLAN qualification

### 5.4 The Making of the Questionnaire: Learning by Doing

The process for creating the questionnaire was begun in early September 2006 and then was sent to UCLAN and other relevant stakeholders for their feedback. The final version of the questionnaire was approved by UCLAN on 23<sup>rd</sup> November 2006. In all 23 Service users and 15 carers took part.

The researchers completed the questionnaires in a semi-structured interview setting and audio recorded them wherever the participants' consent was given. The researchers briefed the participants about the project and obtained their agreement before collecting and recording data. Sufficient time was allowed to ensure the participants understood the information, taking into account language/interpretation needs.

The team carried out interviews with personal contacts and some participants were identified with support from the CDW. There was an issue of not having enough recording devices, so some researchers made notes during interviews and some recorded the conversation and transcribed the conversation later. Although this process was lengthy at times (it could take 1 hour or longer to interview with several hours to note comments) it did provide a rich source of data on experiences and recommendations.

One researcher commented that some of his participants were suspicious of where the information collected would go and were inclined to give only positive responses. However due to the nature of the questionnaire, a more realistic view of their opinions was recorded as some point in the process.

In most cases, the researchers were able to reassure respondents and build a rapport with them, and all the researchers found the interviews interesting. The participants were assured that confidentiality would be maintained and to that end no names were recorded and each completed questionnaire was given a number followed by the initials of the researcher as an identifying code.

Interviews with some participants were very short and with some very long, depending on the length of time and nature of their experiences.

Some participants commented that the interview helped them achieve clarity and, in some cases, closure on their experiences. For many it was the first time they had talked to someone about their experiences and ordeals. We completed the interviews in January and February 2007, ideally they should have been completed by December 2006 in order for us to spend the following 3 months on analysis and report writing.

The completed questionnaires were stored at the DMN office in a locked cupboard. All files, data and documents were stored on computer and the location made known to the whole team. The system for storing data worked well and did not raise any issues from the team.

### 5.5 Learning Points

During the research workshops we brainstormed ideas for questions. This did not prove to be the most appropriate way to decide on questions and focus areas. The process followed did not require us to constantly check back in relation to the focus and did not consider the analysis of the answers in decision making. There should have been a more systematic approach.

We also seem to have defined culture in institutionalised criteria - language, diet, and religion/spirituality. On reflection at the end of the project, there were other categories which were relevant and would have provided a more detailed insight into culture and mental health services. e.g. music, hair care, personal care, superstitions, traditions, family/social relations etc.

The form of questions was varied and somewhat suitable however more consideration should have been given to the analysis of responses. Perhaps a survey of a few open questions based on culture would have given us a better understanding of what 'culture' means to the participants. In practice the questionnaire was large and deterred a few participants from taking part.

For the majority of participants the questionnaire proved to result in in-depth information on Service user's experience and gave ample opportunity for them to provide recommendations. At the end of the research process we have learned that a more appropriate method for arriving at questions for our focus would have been as follows:

- Establish definitions for 'cultural competence' and 'culture'.
- Breakdown focus to gain indicators of focus, e.g. cultural competence = focus, what are the indicators of culture? Language, diet, spirituality, society/community, personal care, music/entertainment, social activities.
- Devise questions based on the indicators.
- Decide how each question will be analysed and review to ensure that the data required to achieve the needs of the research focus is derived.
- Obtain feedback from stakeholders.
- Pilot questionnaire and revise if required.

### 5.6 Focus groups

In order to gain a greater understanding of mental health care provision in Derby, a focus group with Mental Health Professionals from Ward 35 Psychiatric Acute Unit at Derby City Hospital was conducted before administration of the questionnaires began. This focus group provided a more in depth view of the mental health service in the Derby city area, and provided a contrast between the experiences of Service users, and that of service providers/professionals. Participants in the focus group were sourced through contacts of the steering group. This data was captured in audio format and the transcript is not available in this report due to tight time constraints, however, it can be made available upon written request from DMN.

Due to time constraints we were unable to conduct the other focus groups planned (with Service users and carers). Data collected in these focus groups may also have been helpful in the questionnaire design by exploring the concept of culture with participants.

### 5.7 Accessing Participants

Letters were sent to approximately 20 local groups or contacts. Follow-up phone calls were also made several times, however we received very little or no response to this promotion. This method did not work well. Personal visits to groups were a little more productive - but time consuming.

Some Mental Health workers did not want us to approach their Service users even though the Service users showed agreement when approached. Professionals were not readily open to researchers contacting their Service users. Researchers used their personal contacts and these were limited in number. Including the researchers, 1 volunteer and members of DMN staff resulted in a total of 38 respondents (23 Service users and 15 carers). The team used several tools to disseminate information and to access people who could participate in the research.

A poster/flyer was created giving details of the project and requesting volunteers to take part in interviews. The flyer was circulated to:

- GPs surgeries in the local area
- Local shops in Normanton/Peartree area
- Given out at events and conferences e.g. World Mental Health day in Derby city centre and at the Delivering Race Equality/DMN mental health community engagement conference.

The researchers also promoted the project at events and within their circle of contacts, including local groups. Awareness of the project was also generated through steering group contacts.

### 5.8 The Analysis

In order to overcome the restraints of our questionnaire and to complete the project on time, we stopped interviewing/collecting data at end of February 2007. We began the process of analysis in February 2007. We identified 7 questions which yielded extensive information relevant to our focus and we used the other 52 questions to refine and finalise the analytical frame.

We first conducted descriptive coding which we used to determine thematic codes. We structured the coding in data sheets and wrote briefs showing findings of all questions. Quantitative data was also collated and results noted. In so doing we systematically organised the information stored in the following documents on which we used to write the report.

#### January and February 2007

- Spreadsheet created to log data.
- Project plan revised in order to complete project on time.
- Demographic data collated for report.

### March 2007

- Revised project plan
- Analytical framework devised,
- Data input completed
- Personal profiles completed for report
- Mid-month analysis plan
- Data sheets for each section of questionnaire for Service users.
- Analysis documents/briefs for each section of questionnaire for Service users
- Briefs on relevant reports.
- Reflection on methodology
- Cover design for report.
- Data input and analysis brief for Carers.
- Report structure finalised.

At the analysis stage and in the final months of the project, DMN levered in the resources and skills of an experienced researcher who gave the project the support at this final stage. He was able to clarify points on data collection, analysis of data and the research process in a structured clear way. He also gave us a plan which would ensure completion of the project on time, and a structure to analysis which we could easily follow. This plan, explanation of the process and support enabled us to complete a lot of work in a short space of time.

However not all the researchers could commit to the extra hours required to complete the project, so the bulk of the work fell on a few. The team quickly adapted however, and all the researchers worked on areas where they felt they would be most effective and wherever and in whatever time they could. Some worked from home only, some combined working at the Caduceus Health and Well Being Centre (DMN offices) and from home. At the end of the project we realised that ideally this analysis part of the process should be given at least 3 months.

The team acknowledges that a lot could be done differently and at different times, however we have achieved a quality of data and results that we are proud of, despite the fact that the number of interviews completed was much lower than we originally planned. Most of us have enjoyed the experience and built friendships within the team.

### 5.9 Events and conferences attended

The research team attended the following conferences and shared its views:

- CSIP “Making a Real Difference” BME users, carers and survivors work group meeting 12<sup>th</sup> October 2006. Birmingham.
- The Afiya Trust - The National BME Mental Health Network, “Stuck in the system” conference, 18<sup>th</sup> & 19<sup>th</sup> September 2006. Manchester.
- Derby Millennium Network, DRE “Beyond Consultation: Towards Community Engagement” Conference, 10<sup>th</sup> October 2006. Derby.
- Staffed a stall in Derby City centre for World Mental Health day, 1<sup>st</sup> October 2006.
- CSIP, DRE in Mental Health Regional Good Practice Show Case event, 13<sup>th</sup> April 2007. Leicester.

The team found that events discussing Service user involvement and giving Service users an opportunity to express their views and experiences were interesting and useful to our project. Events also gave the team an opportunity to promote the research project and meet with relevant stakeholders. Some conferences were less relevant and took up more of our project working and meeting time than we would have liked.

### 5.10 Support

This research, like any other research, was a collaborative venture and it benefited from the input of a wide range of organisations and individuals.

DMN: DMN provided support to the team on a weekly basis in line with the group's needs and in particular counselling support enabling the Service users within the team to deal with issues as they arose. The CDW and other staff members also provided contact details for up to 20 local BME groups and associations dealing with Service users and carers.

UCLAN: A support worker was assigned by UCLAN to assist the group with the research process and completion of the university qualifications.

The Steering Group: The membership was made up of the project co-ordinator, the UCLAN support worker, and a representative from each of the following groups: Rethink – Beachwood Supported lodgings for BME Service users; Derbyshire Carers Association; Derbyshire Mind; Karma Nirvana ; Refuge UK; Hadhari - Derby African-Caribbean Mental Health; Central and Greater PCT ; Senior Cultural Diversity Specialist-Derbyshire Mental Health Trust; PALS Manager – Derbyshire Mental Health Trust; Asian Women's Mental Health Group; Specialist Registrar – Public Health; Senior Lecturer, Derby University, School of Health, Education and Social Science; The Elms Clinic; Ward 35 Psychiatric Acute Unit; and User Focus Monitoring. The steering Group met on a bi-monthly basis.

### 5.11 A Researcher's personal reflection

When I volunteered to be one of the research team for the Mental Health project for Derby Millennium Network to me it was a time to refresh my skills after 6 years. The project is about Black and South Asian mental health.

We started the project by attending workshops in Birmingham; we had seven workshops with different lessons. These workshops were part of the training to equip ourselves with the knowledge of work that we were going to do.

Personally this project has allowed me to further develop my skills, given this important opportunity of community research has led me to a greater and in depth understanding of mental health issues. Working with the public has given me a greater understanding of our community especially among the minority group.

With this project I have discovered that unity is power. The research project has given me a great experience; there are lots of obstacles about which you have to be bold. Particularly our group was very much supportive of each other. Above all you have to be determined, and to work as a team. I would like to thank you all of my team members for the work we did.

### 5.12 Recommendations for Community Research Projects

*Based on our experience we suggest the following steps for future Community Engagement Projects:*

1. Specialist research analysis/co-ordination support needs to be provided on a full-time basis to support the development needs of the community researchers throughout the duration of the project.
2. The funding for this specialist role must be reflected in the funding award granted to the host organisation. This specialist research analysis/co-ordination support must not be tagged on the back of existing mental health posts.
3. The Steering Group members should have more clearly defined roles and an implementation structure.
4. There needs to be a clearer framework about what the research team/UCLAN support worker relationship will involve.
5. The time commitment asked of community researchers needs to be realistic in line with the scope and scale of the project and be highlighted at the start.

## Section 6: Findings, Conclusions and Recommendations

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Several studies show that the cultural competence of the mental health services has improved in the last five years. The evidence, however, also suggests that the services still do not meet the cultural needs of the BME communities. Joseph Rowntree Foundation's study on the Mental Health Advocacy for Black and minority ethnic users and carers and the studies -"Breaking the Fear of Circle" (2002), "Inside Outside (2003)" and more recently the Young Minds "Minority Voices"(2005) all suggest that both Service users and carers are dissatisfied with the main stream mental health services.

In this study, we have made efforts to identify gaps in the mental health services for BME/BCD & dual heritage Service users and carers. In so doing we have focused on the experiences of 23 Service users and 15 carers aged 18 and over.

They have candidly shared with us their observations and experiences and have demystified the cultural competence of the Mental Health Services in Derby city. Their primary concerns are the communication and care which structure their cultural interface with the Mental Health Services in Derby city. Our aim is to report their opinions, feelings and proposals and to recommend improvements which may further advance the cultural competence of the Mental Health Services in Derby City. We begin with the demographic profile of the BME community in Derby City.

### 6.1 DEMOGRAPHICS

According to the census of 2001 the population in Derby City is 221,708. Of that 12% count themselves to be Asian, Black or Mixed race. The highest concentration of non-whites is in the ward of Normanton which has a total population of 13,506 of which 52% are white 48% are non white (Black, Asian or Mixed Race). The participants of this research are predominantly residents of the Normanton area.

<b>Ethnic Group</b>	<b>Number of people</b>	<b>% Derby City</b>	<b>of Derbyshire</b>	<b>total England</b>
White	193,881	87.4	98.5	90.9
Mixed	3,968	1.8	0.5	1.3
Asian or Asian British	18,533	8.4	0.5	4.6
Black or Black British	3,895	1.8	0.2	2.3
Chinese	857	0.4	0.2	0.4
Other ethnic group	574	0.3	0.1	0.4
All people	221,708	100.0	100.0	100.0

### 6.2 FINDINGS

#### Core data can be found in Section 7. 4: Appendix 4

Communication and care were the primary concerns of the Service users and carers who participated in this research. They preferred to talk in the language of their own choice; they preferred to talk to GPs, to the trusted members of their family, to their close friends; some of them preferred to discuss their illness with their faith representatives; they did not trust professional interpreters; and they liked to be understood better and to be able to fully grasp the information and advices of Mental Health professionals. They preferred to get treated at their homes and in their communities. Some of them liked to get religion, gender and ethnically specific treatment. All these preferences and choices clearly point to the approach that the mental health services in Derby city need to consider in evolving culturally competent services. In this section, we present the experiences and feelings of the participants. The aim is to voice their legitimate concerns that point to the cultural gaps and to recommend improvements.

#### **1. The Mental Health Services in Derby city generally meet the language needs of members of BME communities. But some participants felt marginalised, misunderstood and misguided because of language related reasons.**

19 out of 23 (82%) participants felt that their language needs were met. All 23 participants wanted to communicate in their preferred language to service providers and they observed beneficial effects of the frequent communication on their mental health. The use of the preferred language, they told us, helped them to 'express their feelings' and to have 'dialogue with the service providers'. A participant, who had a good experience of treatment, stated that, "The GP was really helpful - he spoke to me in my own language".

The Mental Health Services, in some cases, partially fell short and did not meet the language need of the participants. One participant said, "I had my son to explain" while the other stated, "I spoke English but it's not as good and I wasn't able to understand everything. I wished there was someone in my language to explain". Even those participants who were given the interpreter service felt misunderstood, one participant stated, "I know doctors can use interpreters but I don't like them. Sometimes they do not interpret in right way".

15 out of 23 participants preferred to talk in English of which 4 (27%) stated they failed to understand the information about their medication. Out of the 8 respondents who did not prefer to speak English, 6 (75%) stated that they were either unsuccessful to understand the information about their medication or they were not given any information.

#### **2. Some Mental Health Service providers in Derby City, the participants noticed, imposed their own cultural frames on them. This behaviour had not only adversely impacted on their treatment but it had generated the feeling of disrespect and rejection among them.**

The presence and availability of BME health care professionals is important to BME Service users. 6 participants (Service users and carers) mentioned the need for more BME staff. However, with regards to South Asian doctors and counsellors, some participants noticed that the cultural affinity between them and their doctor was a problem. Some participants observed Asian doctors made assumptions and generalisations about them based on culture and often disregarded their personal views and opinions.

One participant reported that

***“Assumptions were made because I am Asian I would behave a certain way and I was not listened to by doctors who seemed to talk to my husband more than listen to me, especially Asian doctors”.***

Another participant made a similar comment, stating;

***“I had mainly Asian doctors, but none of them explained anything to me as an Asian woman or to my husband. I felt maybe because they felt or assumed we already understand.”***

The participants drew comparison between the Asian and non-Asian doctors and asserted that latter were more culturally sensitive. A participant narrated her experience of both categories of doctors and stated

***“In my experience Asian doctors seemed to ignore their own ‘Asianess’ and be more adamant and not listen to Asian patients. They should have been of more help to me - I expected they would be but I was listened to only by white doctors.”***

Another participant felt rejected when her Asian counsellor judged her.

***“The counsellor was an Asian bloke and he said ...something like ‘us people we all go through things like this’. It was something of the sort of relevance that made me feel you should just go away and deal with things. I remember feeling after that remark, if it had been a white person I would’ve got more help. I don’t feel I’m going to get the same kind of support with an Asian person because I question whether I’m going to get judgments on me based on our backgrounds.”***

**3. The Mental health Service providers in Derby City have limited understanding of cultural needs and they, many participants observed, emphasize merely on language and disregard dietary, religious, emotional, and medical needs of the Service users of BME communities. Many participants felt unimportant, and ill-treated.**

Ticking a Box Majority of the participants felt that their cultural needs were not met. They were not even asked about them. Some of them were asked about a few usual cultural needs such as language and diet. One participant interpreted the cultural competence of the service and stated that,

***“Every time I go to the doctor I am asked if I need an interpreter, even though my first language is English, to me this shows that language is the only cultural need that the services are concerned with” Another said, “In Derby City General hospital about 2 years ago I was asked about dietary needs only... At Kingsway I was asked nothing.”***

One participant considered the cultural practices of the services ***“Just a form of exercise to tick a box, but not about my needs.”***

Foodstuff 14 out of 17 (82%) participants who were hospitalised stated that they were not asked about dietary needs. Only 3 participants declared that they were asked about dietary requirements, one of these commented that vegetarian meals were provided and that her dietary needs were therefore met.

However, the dietary requirements of some of the participants were not met because the choice was limited. One participant wanted to have West Indian food and was being told it was “too expensive”. The cultural orientation of food, some participants observed, was better in the City hospital because “it cater to many different cultures.”

### Faith

Religion and spirituality are components of culture which were relevant in the lives and treatment of all the participants. 18 Service users (78%) informed us that they had some form of religious belief. The remaining 5 participants, who described themselves as having no formal religion, indicated that they did in fact have a belief system and practised different forms of spirituality.

6 participants showed greater interest in faith representative as service providers while some considered the places of worship significantly important for experiencing serenity.

Although participants indicated that they would like to be able to speak to their faith representative or someone in the religious community about their mental health problems, there was a common sentiment that lack of awareness of mental health issues and the prevalence of stigma was a deterrent to the Service users seeking this support. As one participant stated

***“I think faith centres should talk more about mental health in their communities and be more open about this, to reduce stigma and encourage people to use community support and to help them”***

Some participants informed us that they had used religious practices as a means to self-help while others practiced yoga and meditation as a coping mechanism which helped them in the recovery process. Despite the religious behaviour of the participants, only 5 of the 23 participants had ever been asked about their religious and spiritual needs by a mental health professional. 13 out of these 17 hospitalised (76%) participants stated that they were not asked about religious/spiritual needs. Indicating that during the course of their treatment or illness the majority of participants had no opportunity to express their religious or spiritual needs or to have them fulfilled. Even those who had been asked about religious/spiritual needs received generic and inept services.

One participant felt unwell because no one helped her to pray on time, she said,

***“My drugs help me sleep, but sometimes I miss prayers and that makes me feel unwell.”***

### Empathy and Compassion

Some participants pointed out the lack of compassion especially among GPs. A participant stated,

***“Sometimes I go to see the nurse instead of a doctor because they are so much more understanding and empathetic.”***

Another participant reported her experience and commented;

***“I don’t think GPs have heart and compassion, they have medical knowledge but they don’t have the emotional/psychological training to deal with patients with mental health issues.”***

A carer whose mother has a long term illness told a story about the uncaring behaviour of her GP. The GP told her that her mother would not have a good quality of life and she would have a short life expectancy. The way in which this information was communicated had generated despair and depression. The participant and her mother felt that the GP lacked caring and compassion. She told us that;

***“I have spoken to my mum’s G.P. about her being depressed ...they’re not helping the situation because they call her a hypochondriac and she’s not. They don’t understand the part the medical services have played in her emotional health...You’re bound to be depressed when you’re being told... you haven’t got long to live. They played a big part and I was reminding them of that part and that she needs help, and if you’re not going to help at least treat her with respect.”***

Two other participants also experienced ill-treatment.

***“No-one spoke to me or helped me work through my problems in hospital - I was left to wander around, being offered drugs by other patients, staff did not seem interested in me. The whole experience was very isolating and scary and I would avoid ever going to hospital again.”***

***“Staff sat in their office and patients were left, ignored - as almost as this was a big stigma.....”***

Some participants felt they were being rushed when they visited their GP or counsellor. They expressed the desire to have more time to talk and did not get it and ended up feeling unimportant. A participant described her feeling,

***“A professional service - not a conveyor belt one in one out”***

Majority of the participants observed that their GPs prevent them seeking additional help.

A participant declared that

***“I got knocked back 3 or 4 times... I had to literally force them into letting me see somebody.”***

Another participant interpreted the behaviour of her GP and said that,

***“My G.P. agreed to get a referral and I had to ask several times before he agreed.”***

Many participants noticed that the service providers heavily relied on medication rather than other methods of treatment. A participant reported that,

***“They just want to prescribe you meds, that’s always the issue, I just don’t go now, I’ve found different coping mechanisms now... I knew I needed to speak to somebody.”***

Another participant even questioned the very foundation of psychiatry,

***“How can a pill help you deal with things, does it talk to you, and does it ask how you’re feeling, does it befriend you?”***

Some participants reported that they observed that their GPs did not discuss with them their mental health and merely gave attention to their physical health. One participant commented,

***“My G.P. never discussed this (mental health) with me in the 10 years after my admission to hospital....my GP never even asked me about my stay in hospital or my mental health - until I mentioned it recently.”***

Some participants even felt that once a referral was made or a patient was hospitalised they become ‘someone else’s responsibility’, and the GP was no longer concerned with that patient’s mental health.

**4. The Mental Health Services in Derby City include an elaborated network of service providers which partially meet the needs of the Service user. However, the participants noticed a lack of communication among the service providers which had compromised their treatment and recovery.**

The list of persons and groups with which Service users and carers may communicate with at any given point in their care and treatment is quite extensive. This list includes GPs, interpreters, counsellors, nurses, hospital staff, social workers, mental health workers, support groups, psychiatrists, psychologists, psycho therapists, friends, family members, faith representatives. Indeed, there is a wide range of people available within the services for Service users to communicate with.

Although there is no shortage of service providers, it seems that frequency of communication was concentrated mainly between the Service users, their GP and their families. This constitutes a core network of Service users and provider which is central to the management and cure of mental illness.

The focal point of contact with services is the GP surgery. 20 participants (both carers and Service users) reported that the GP was the first place they went to seek help/ advice. Most of these participants reported making regular visits to the GP especially in the early stages of illness.

10 of the 23 respondents (Service users) indicated that their family provided regular support and that this support was vital to their recovery. As one participant explained,

“Trips out with family. They benefit me as I am with my own people. Something that some of the previous people involved in my care did not seem to understand.” Another participant explained the importance of family.

Two other participants explained the importance of family stating,

**“My Family has been extremely important and helpful; if it weren’t for them I would be much worse off” and “If I needed to go to someone I’d go to my family”**

Many participants, however, observed that there had been little or no communication between their GP and family which sometime has created problems for them. A participant elaborated on this point,

**“Persons with mental health problems should be able to get family counselling as well as individual counselling because so many problems originate within the family or are complicated by family discord and misunderstandings.”**

Some participants pointed to the benefits of involving family in the counselling. They received better support from their families once their families had gained a better understanding of their illness. A participant described,

**“More members of my family are aware of my illness now and I can talk to them if I feel stressed.”**

Another participant explained, **“I got my family now, my children; they all understand what depression means and give me support.”**

Among the carers, 7 of the 15 participants identified the communication gap between them and the service provider as an obstacle and stated that it had made it significantly challenging for them to successfully act as carers. They said that they would have benefited from having someone from the services explaining the illness of the person they were caring for. They said that they needed more support from the services on who to contact for help. One participant concluded that;

**“Definitely there should be a support network in place between the professionals, the carer and the patient. Because each profession has their own role to play in supporting the patient, but so does the carer, and it’s the carer that is with the patient most amount of time. And although they (the carer) have no professional background they are most aware of the patient’s needs and it’s important that they are included in the treatment and care of the patient.”**

Two respondents mentioned the need for more partnership and co-ordination between the services. One respondent specifically indicated that there should be more feedback and consultation between GPs and other health care professionals involved in the treatment process. And that a regular update and monitoring system should be established to review their mental health.

**5. The Mental Health Services in Derby City have made mental health services available both within communities and outside it. The participants (both Service users and carers) however, either had little knowledge of the location and nature of the services or they preferred to use those service places where they felt comfortable. The participants noticed that the information and choice of the service places influenced the outcomes of their treatment.**

The participants identified four places where they received help and advice- home, community, GP and hospitals. 18 participants (both Service users and carers) generally noticed a lack of mental health services available to them in the community. The sense is that the term community has been largely used by participants in reference to their locality, in this case within the Derby city area and more specifically around the Normanton area.

When the participants were asked specifically to list any local mental health treatment and/or support services that they were aware of, very few services were mentioned and in several cases participants were under the impression that no such services existed within the community.

Of the 17 respondents who answered this specific question, 4 of them stated that they didn't know of any mental health services available in their community, and 5 stated that there "are none".

A participant stated,

***"There should be some good organisation independent of the GP where someone can go for counselling. I can think of many people now who need this but they don't know anywhere to go."***

When we asked the participants to list the places where they would like to get services they suggested that the services should be made available at those places where Service users feel most comfortable and at ease, and which are more conveniently accessible to them in their daily lives.

There was a sense that the participants felt that they had to go out of their way to access services, and these services - and by extension recovery and wellness - should be more integrated into their day to day routines. Several participants indicated that they felt most comfortable within their home and at their respective faith centres.

As one respondent explained;

***"Home visits because they are better setting, more comfortable in my own surroundings".***

Some participants (both carers and Service users) even suggested the need for more home visits/ home therapy sessions by doctors and other health care professionals

***"It would have helped me if someone came to my home to talk to me about this, I would have used this sort of service."***

14 of the 23 participants (61%) expressed a desire to see more mental health care services within the community. One respondent stated, “I would like them to have somewhere nearby, like in Normanton, where somebody can get help quickly and not to waste months and months.”

A similar suggestion came from another participant who advocated for, “community based counselling for women”. Perhaps there could be counsellors at some of the local community centres, that way people could go to someone from their own group who understands their cultural, religious and ethnic background.”

The participants provided a list of the places which can be transformed into the care locale; some of them are health centres, local community centres, and offices of the Community associations, Mosques/Faith Centres, libraries, Schools/Universities, GP surgery, parks, drop in centres, women’s centres, and job centres. There was a clear expectation among the participants that the GP surgery should offer counselling either on site, or alternatively, provide vital links to other counselling/support services available within the community.

In other words the GP surgery should be a bridge to a variety of community based mental health services. As one respondent suggested; “GPs need to have closer links with the Mental Health services that are available, and a referral system and a feedback system.”

Many participants reported their experiences of hospitalisation and some of them had unpleasant memories. The main sentiment expressed was one of taking time away from the hospital environment to be with family or other community members with similar experiences, and people who had a more intimate understanding of their culture. A specific example given by one respondent was, “Something like the DACHMA. They come and take you off the ward, you get a Caribbean meal. I found that beneficial. I was around other people with mental illness, somewhere you could relax with your own.”

### **6.3 CONCLUSIONS**

The findings reveal the gaps that exist in the provision of mental health services to the members of BME communities. The following gaps feature prominently in the experiences of the Service users and carers.

Service users and service providers have differential understanding of the scope of cultural needs. For example, the Service users consider personal care, food provision, spirituality, or configuration of social relations as a part of their culture. On the contrary, the service providers merely include language and diet in their interpretation of cultural need.

Service users and service providers differ significantly on the process of treatment and recovery. For example, GPs sometime ignore the personal histories and individual characteristics of the Service users; similarly, the Service users prefer to get treatment at their homes while the service providers seem to suggest distantly located services away from the families of Service users. Also the Service users want more talking and spiritual therapies while the service providers place emphasis on physical therapies/medication.

### **6.4 RECOMMENDATIONS**

On the basis of our analysis we recommend the following steps which may improve the quality and appropriateness of the mental health services.

- A policy forum should be established, involving all stakeholders including Service users and carers. This forum will work on the cultural competence of the mental health services in Derby City focusing on the scope of the cultural needs of the Service users and culturally responsive treatment and recovery process. The forum should deliver a uniform and agreed policy guideline for the service providers in Derby City.
- There is a need to monitor the cultural performance of GPs, and other staff members of mental health services to ensure that performance is in line with DRE requirements.
- It is vital to ensure that GPs take into account the cultural background of Service users, their individual histories and their views about the process of treatment.
- Mental Health Services should increase the involvement of families and carers in the treatment and recovery process in line with Service user's wishes.
- Increased access to talking and alternative therapies, making them available as standard in mainstream mental health services.
- Information about treatment should be made widely available at community level in appropriate languages
- The Mental Health Services should develop innovative and creative ways of delivering services at the community level and improve on existing services in the community.

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## Section 7.1: Appendix 1 - Questionnaire

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### Black and Asian Mental Health Research Project

**Research focus:**

The group intends to carry out research on the experiences of 18+ Black and South Asian service users and carers in order to make recommendations for cultural competence in the Mental Health Services in the Derby City Area.

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## QUESTIONNAIRE

ID No:

### 1. Have you ever used Mental Health Services?

- Yes - Go to Section 1
- No - If you are a carer, go to section 2

## SECTION 1

### 2. What is your understanding of Mental Illness?

### 3. When did you first realise that you had a mental health issue?

- 0-3 months
- 3-6 months
- 6-9 months
- 9-12 months
- 12-18 months
- over 18 months

**4. What did you do about this?**

**6. How long was it before you received treatment?**

**6. Where did you first go for help when you realised you had a problem?**

- GP
- Family
- Friend
- Church
- Local Voluntary Group
- Other: Please Specify.....

**7. How did you feel at this time?**

**8. Did you see a GP?**

- Yes
- No

**9. If yes, was your GP helpful?**

- Yes
- No
- N/A (Did not see GP)

**10. Which of the following services did you use?**

- Day care services
- Hospital Psychology unit
- Private therapy/counselling
- Social Services

Other, please specify.....

**11. How do you feel about the Service you received? (please note any comments below on the next question.)**

	Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied	Service was not used
Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Police	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital Staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Psychiatric Nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psycho-therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chaplin/ Faith Representative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify:.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**12. What more would you like to say about any of the services you used? Please provide as much information as possible. Where applicable please give details about how services were good/bad and what changes you would like to see made.**

**13. Do you have any recommendations about how mental health services can be improved?**

**14. Could you provide us with some more information?**

*Interviewer prompts: (For example, **who** should do this job? **When** do you think it should be done? **How** should it be done? **Who should be involved** in doing or developing it? **Where** should services be based? **What kind** of services should be delivered? **How** can changes be made to ensure they are delivered more appropriately, **Where** should they be advertised?)*

**Let's talk about culture and language now**

**15. What is your preferred language?**

**16. Were your language needs met by anyone in the health service?**

Yes

No. **please explain:**

**17. Were you asked about any specific dietary needs**

Yes, How? Please give example/s

No. Please explain

**18. Were you asked about any specific religious/spiritual needs ?**

Yes. How? Please give example/s

No. Please explain

**19. Do you have any other cultural needs, and were you asked about them?**

Yes, How? please give example/s

No, Please explain

**20. Do you have any other comments about how culturally sensitive services were?**

Yes

No

**21. Do you have any recommendations about how the service could be improved to meet your cultural needs?**

*Interviewer prompt: Remember to break this down, look for answers in relation to language, food, staff, dress, mixed gender wards, praying facilities etc.*

**Now I'd like to talk a bit about your family and your community.**

**22. Were members of your community/family/friends aware of your situation? (please tick all that apply)**

Community

Family

Friends

**23. What was their reaction?**

**24. How helpful/supportive were your:**

	Very Supportive	Somewhat Supportive	Neutral	Somewhat Unsupportive	Very Unsupportive
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**25. Any other comments?**

**26. How often did your family or friends visit you while you were in hospital?**

	Daily	Weekly	Monthly	Never	Other, please specify
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**27. Did you want your family/friends to visit**

	More	Less	No Difference	Not at all
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please explain why:**

**Lets talk about other types of support**

**28. Do you have regular support from a carer(s)? If yes, how many?**

Yes, **How many?**

No

**29. If yes, is your primary carer:**

Family

Friend

Other, Please specify

No carer

**30. Do you have your own informal support networks?**

Yes, **If so, what are they and in what ways are they beneficial?**

No

**31. Apart from the NHS, what mental health services are available for people with mental health problems/issues in your community that you are aware of? Please list.**

**32. Are there any other types of mental health services you would like to see in the Community?**

Yes, Examples

No

**33. Is there anything else you would like to say about what would have helped you?** *Prompt: What improvements would you like to see?*

### Lets talk about Treatment and Medication

**34. Were you given medication?**

Yes

No

**35. Were you informed about the medication?**

Yes

No

**36. Did you understand the information provided?**

Yes

No

**37. What information were you given about your medication? (What it was for, dosage, when to take, side effects and contraindications)**

**38. Did you consent?**

Yes

No

**39. If yes, how did you give your consent?**

Written

verbal

N/A (No consent given)

**40. Were you told about possible side effects?**

Yes

No

**41. Were you told about alternative therapies?**

Yes

No

**42. Have you ever been hospitalised?**

Yes

No, **If no, please go to next section**

**43. If yes, were you ever:**

Isolated

Segregated

Other, Please specify

**44. While in hospital, how involved were you in the planning/design of your care plan?**

Very Involved

Somewhat Involved

Neutral

Rarely Involved

Not at all Involved

**45. How involved was your carer in the planning/design of your care plan?**

Very Involved

Somewhat Involved

Neutral

Rarely Involved

Not at all Involved

**46. Did you agree with it?**

Yes

No

**47. Did you understand it?**

Yes

No

**48. After you were discharged from hospital what follow-up community support was made available to you?**

**49. Do you have a Community Psychiatric Nurse?**

Yes

No

**50. If yes, How helpful is she/he?**

Very Helpful	Somewhat Helpful	Neutral	Not very Helpful	Not at all helpful
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**51. Were you allowed at any time during your stay in hospital to leave unescorted?**

- Yes
- No

**52. How were you treated by doctors?**

	Very Bad 1	2	3	Neutral 4	5	6	Very Good 7
When you were on the ward?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When you returned home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**53. What improvements do you want to see in the delivery of mental health services? Please list and explain**

**54. How do you feel about yourself now?**

**SECTION 2**

**Carer**

**Core Data Questions**

**1.1 Age last birthday:**

- 15 or under
- 16 - 18
- 19 - 21
- 22 - 24
- 25 - 29
- 30 - 39
- 40 - 49
- 50 +

## 1.2 Gender:

- Male
- Female
- Transgendered or transexual

## 1.3 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

#### 1.4 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

#### 1.5 Are you a:

British Citizen

Refugee

Asylum Seeker

Other (please explain)

#### 1.6 What is your first language?

#### 1.7 Which languages are you fluent in?

Spoken

Written

#### 1.8 What is your religion:

None

Christianity

Buddhist

Hindu

Jewish

Muslim

Sikh

Other (please explain)

**1.9 Sexuality:**

Lesbian or gay woman

Homosexual or gay man

Heterosexual or straight

Bisexual

Do not wish to answer

Other (please explain)

**1.10 Do you have a disability:**

Yes (please explain)

No

**THANK YOU FOR YOUR PARTICIPATION**

## Section 7. 2: Appendix 2 – Language & Culture Results

### DATA SHEET QUESTIONS 15-21

	Q15	Q16	Q17	Q18	Q19	Q20	Q21
ID No	What is your preferred language?	Were your language needs met by anyone in the health service?  Yes No - explain	Were you asked about any specific dietary needs?  Yes - how No - explain	Were you asked about any specific religious/spiritual needs?  Yes - how No - explain	Do you have any other cultural needs and were you asked about them?  Yes - what No – explain	Do you have any other comments?  Yes - comment No	Do you have any recommendations about how the service could be improved to meet your cultural needs?
2 LP	English	Yes	No, I do not remember. You asked for West Indian food but told not enough demand and too expensive.	Yes, no need	Yes. There was a nurse that helped me with my hair that was a Black nurse, that was nice.	No	Hair care - down to individual nurses. Food - Totally lacking. There should be Caribbean food on menu, there was one dish of stewed red peas and rice. City is better than Kingsway as they cater to many different cultures.
3 RR	English	Yes	Yes, I think I was asked if I was vegetarian and appropriate meals were provided.	No, The subject did not come up - anyway I did not have any specific needs of this sort.	No, Did not have any other needs and was not asked anyway.	Yes, In my experience, the service was not culturally sensitive - assumptions were made because I am Asian I would behave a certain way. I was not listened to by the doctor who seemed more than listen to me, especially the Asian doctors.	Asian doctors need to be trained not to ignore their own culture and the support they can give to Asian patients. In my experience Asian doctors seemed to ignore their own 'Asianess' & be more adamant & not listen to Asian patients. They should have been of more help to me - I expected they would be but I was listened to only by White doctors. Asian doctors should receive training on their impact on patients of the same culture/appearance/ethnicity.

4 RR	Punjabi & English	Yes	Not relevant	Not relevant	Did not have any other needs	<p>Yes. It is easier for me &amp; it would be helpful for me if my GP could talk in my own language.</p> <p>Now, My Gps is very good at understanding but I can't talk about things in my own in my own language which would be easier for me sometimes, even though I can speak English.</p> <p>My GP now is very understanding and my English is better now. Before when I was ill my English was not so good and it was helpful for me to be able to speak in my own language.</p>	I know doctors can use interpreters but I do not like them. Sometimes they do not interpret in right way; they should be very careful how they are answering doctor's questions.
5 RR	English	Yes	N/A	<p>Yes, I had an Asian therapist – due to my background and because of the issue of my friend passing away due to black magic.</p> <p>I was asked if it would help as I had someone who was Asian and I said yes because they would have some understanding of the issue.</p>	<p>Yes, Not making assumptions based on your ethnic origin or maybe they need to be culturally aware.</p> <p>Sometimes Asian doctors don't have cultural awareness. They may have had a more mainstream upbringing they may not</p>	I was asked if I'd prefer an Asian therapist.	GP's should have access to information about comments that people have made, like this research, about cultural awareness and they should be trained using case studies and people who have been through it, been through a bad experience. There should be more service users involved in training for doctors.

					have cultural knowledge.		
6RR	English	Yes	Not applicable	Not applicable	No	Yes. This would apply if I was seen by a counsellor, then that counsellor would need to have some knowledge of Indian society, about arranged marriages and love marriages in particular.	Professionals need to be able to have dialogue with patients in their own language, and be aware of their cultural differences and the traditions in that society so they can help them.
8 HM	English	yes	Not applicable	Not applicable	No	No	Not applicable
9HM	Bengali	Yes	No	Yes, worship	No	No	Not applicable
10 HM	Shona	Yes	No, not mentioned	No, not mentioned	No	No	Left blank
15 AM	English	Yes	No	No	Yes. I was not asked about my needs, and I had no opportunity to express them.	Yes. Every time I go to the doctor I am asked if I need an interpreter, even though my first language is English, to me this shows that language is the only cultural need that services are concerned with.	I would prefer a female doctor personally. Sometimes I go to see the nurse instead of the doctor because they are so much more understanding and empathetic. So more female doctors should be available to treat women.
16 AM	English	Yes	No	No	No	No	Yes I am from a Jamaican background and we tend to ignore and deny mental illness until the problem becomes unmanageable. Our community could use some education to raise awareness and reduce stigma of mental illness.
22 NH	English/Patois	Yes	N/A	No	No	No	N/A
23 NH	Punjabi	Yes	No	No	No	No	Plus staff needs to be given training on these- This should be mandatory.
30 RR	English	Yes	N/A	N/A	No	Left blank	Left blank
33	Nyanja	Yes	No.	No.	No	N/A	N/A

HM			I was not asked about it.	Not mentioned.			
38 MK	English/Punjabi	Yes	No. At Kingsway hospital there was no choice of food, I was not asked about my dietary requirements.	Yes. Just a form of exercise to tick a box, but not about my needs.	Yes. In Derby City General hospital about 2 years ago I was asked about dietary needs <u>only</u> . No. At Kingsway I was asked nothing and no option available.	Yes. From 1986-2001 approx I feel I did not have the appropriate help in terms of cultural sensitivity, it is only within the last few years this changes for me.	It would have helped to have someone from my background and culture, as point of contact, as it would have helped me to understand what was happening to me.
39AB	English	Yes	Yes	Yes	No	No	No response
40AB	English/Punjabi	Yes	Yes	Yes	No	No	No
51 AS	English	Yes	No	No	No	Yes. If services were culturally sensitive then I believe services would be more readily available to the sufferers of conditions described in type 1 of my answer to question 2 section 1 ( <i>"winter blues" longer term seasonal depression, stress, SAD</i> ) The fact that access to such MH services was so difficult in the end I gave up trying to access these services that are culturally insensitive.	As above
52 AS	Bengali	No. I spoke English but its not as good. I wasn't able to understand everything. I wished there	No. When I went in then was a long time ago, this was never asked.	No. No one ask me they thought I was obviously different.	No	No	No response

		was some one in my language to explain.					
55 AS	Bengali	No. I had my son explain	No	No. No one ask if the drugs were halaal, and we didn't know. No one said that I would fall asleep and sometimes I miss my prayer.	No	No	More things in my language, more women doctors more places to go and visit at home. Check if drugs are halaal and should be labelled.
56 AS	Bengali	No. It was not explained in my language, only family inheritance.	No. No one asked.	No. No one asked.	No. Nothing.	No.	As before more people who understand from my background.
73 HM	English	Yes	No	No. Not mentioned	No Not discussed	No	No response
58 AS	Punjabi/Mirpuri	No. Interpreters were available but I prefer that the doctors be able to communicate directly in my care the GP did but sometimes that the GP isn't there then that's a problem.	No. I knew that my drugs should be OK, but we didn't know if they are halaal.	No. My drugs help me sleep, but sometimes I missing prayers and that makes me feel unwell.	No. My doctor is female so that helps.	No.	I am not sure but as I have said earlier more home visits, better language facility, they should know if the medication is halaal, and better options than just drugs and prescriptions, more support for family so they may understand the difficulties of being unwell.

## Section 7.3 Appendix 3 – Service Users Data Results

### Questions 1 to 54

**1 Have you ever used mental health services?**

Yes                    23  
 No (carers)        15

**2 What is your understanding of mental illness?**

1	The mind is not working in a logical and coherent way.
2	When your mind is not working in the normal expected way. When you have problems making decisions or relating to others.
3	When a person doesn't feel comfortable with themselves, getting shaky, worrying too much, getting aches and feeling ill when there's nothing physically wrong with them. Feeling ill without any illness and then the doctor says you are depressed. Mental illness is a kind of depression which a person passes through and does not understand what it is.
4	When you find it difficult to deal with your own emotions. It's about your emotional well-being.
5	Its and imbalance of one's mental well-being. It can be an imbalance possibly caused by one's environment, nutrition or life-experiences.
6	When you don't think and your brain cannot work properly doing unusual things.
7	Mental illness are people who have their brain imbalance.
8	It is about when your brain does not do well about your daily work, or not connect correctly causing problems with your day to day living.
9	Not being able to function properly on a day to day basis
10	Anything which affects your ability to function properly and think clearly or rationally
11	My understanding of mental health is about mind, body and behavior and, its relates to cognitions
12	Mental illness is everything about a person's health.
13	Mental illness is when people, for whatever reason (background experience, family, accidents, personal illness) find it difficult to cope and deal with everyday challenges and issues.
14	Mental illness cannot always usually quantified although it is real as a psychological illness sometimes can be violent and do things that a normal person cannot do.
15	That I have chemical imbalance in my brain and that I only feel better with my medication. I have a depot injection, which is what keeps me well. Also my understanding of mental illness is when I may feel depressed or sad.
16	Illness that affects the mind.
17	When I can't control myself.

18	Two fold initially (1 in 4 people suffer from mental illness) 1. 'Winter blues' - longer-term seasonal depression, stress, SAD, mental illness that is neglected by sufferer and service providers. 2. This gap in mental health services is filled by charities e.g. MIND or Social support network. However, as to how well this gap is being filled. This is not withstanding above: (2) clinically labelled- recognized illness of psyche, e.g. schizophrenia and bi polar.
19	You (are) suffering from an emotional state of illness.
20	I feel unwell most of the time and I think it do with not being well all over.
21	Depression and things that make you not feel well physically, emotionally etc.
22	My understanding of mental illness is when you are not able to function as wholly or as normally when you are physically, emotionally, spiritually well.
23	When your brain dies not connect causing problems with day-to-day living.

### 3 When did you first realise that you had a mental health issue?

0-3 months	1
3-6 months	1
6-9 months	2
9-12 months	3
12-18 months	0
Over 18 months	16
Total	23

### 4 What did you do about this?

1	No response
2	Sought private counseling.
3	I went to see a GP. I said something's wrong with me, I don't know what. First he sent me to hospital to checkup what's wrong with me. When he couldn't find anything wrong with me, then he found out that I'm suffering with depression and he gave me tablets.
4	Because I was really young I closed up. I couldn't talk to anyone about it. Then I went to my GP because a friend had passed away and I couldn't handle that. I was about 15 or 16, and when I went to see the child psychologist we ended up talking more about family issues as well as that issue.
5	Went to the doctor, my local GP, to discuss my personal situation at the time.
6	Decided to see a GP with my family.
7	You go to the doctor.
8	Visited GP

9	Nothing for a while. I tried to cope on my own and prayed to God for help. Eventually I asked my GP for a referral to a counsellor.
10	Nothing, tried to go on with life as normal. Then I went to see private counselor/ psychiatrist.
11	Family supported me to go to my GP.
12	Nothing at first.
13	Nothing for a very long time. I don't think that I realized that there was an issue at first. Then when I did realize I went to see my GP. I spoke to my husband at first.
14	I went to see a GP.
15	Went to see GP, initially, who treated me with injections and tablets but then after I was referred to Kingsway hospital.
16	Initially did nothing as I didn't know what was wrong but eventually went to the doctor.
17	I didn't know what to do, I took an overdose.
18	Went to GP in winter and feeling 'winter blues' SAD seasonal affective disorder, researched the condition, symptoms surrounding it, treated, no.....for that treatment, text on psychology.
19	Nothing
20	GP.
21	GP.
22	GP.
23	Visited GP.

## 5 How long was it before you received treatment?

1	Between 6 months and 1 year.
2	Few weeks.
3	Received attention straight away. When diagnosed after few months of checking was given medicine straight away so received treatment after a couple of months.
4	It was a matter of weeks between seeing the GP and seeing the psychologist, because I was a kid I think they had to deal with it straight away.
5	I didn't receive any treatment. The GP listened to my issues and gave me some painkillers for headaches I was having. There was no treatment or referral. He gave me a sick note for time off work to rest.
6	Immediately
7	Immediately
8	It took time before I was treated
9	I am still waiting for the referral.
10	6 months
11	It did not take long in fact to my surprise one week.

12	Couple of weeks
13	I received treatment straightaway in terms of a prescription, and I was referred to a counsellor, who I saw in a few weeks. There was no issue about having to wait too long.
14	Immediately
15	Cannot remember although everyone including family and work colleagues knew I was not well.
16	3 months.
17	Not sure.
18	Not being treated, GP sneered at me. I haven't been back to GP ever since for any ailment even for other thing, e.g. cold
19	When I was in hospital
20	No response
21	I was told to take prescription.
22	GP prescribes drugs on first seeing him.
23	Immediately.

**6 Where did you first go for help when you realized you had a problem?**

GP	14
Family	5
Friend	0
Faith Centre	0
Local Voluntary Group	0
Other: Please Specify	1 None, 2 Private Counselling, 3 psychiatrist, 4 hospital
No response	1

**7 How did you feel at this time?**

1	I thought when the situation get better my depression would lift.
2	Very stressed, physically unwell, very depressed.
3	I was feeling quite down and quite poorly, feeling like I'm very ill, like I can't express my feelings to anyone, I can't tell anyone how I'm feeling. The doctor came to see me at home actually because there was not enough time to talk to me in the surgery so he came home. I was feeling tired all the time. Then he found out that I'm suffering with depression.
4	I was at school at the time and found it difficult to cope with things. I knew from my studies that this wasn't right and thought I had to see a doctor. I tried talking to family first but got no help there. I felt suicidal, alone, like I couldn't go on anymore.
5	I felt very depressed. I felt depressed because I lost my father and I was going through lots of issues with my family over their disapproval of my marriage.
6	Very disturbed.
7	Disoriented.

8	Confused or very disoriented.
9	Frustrated, confused, depressed, helpless.
10	Stressed, confused. I had a breakdown at work and was taken to the hospital. I felt helpless.
11	I felt sad, embarrassed. Low in mood.
12	Awful, stigma.
13	Not very good. I felt like I really could not cope. Everything would aggravate me, everything was a problem, I did not feel confident. I had low self esteem. I couldn't cope with the little things. I felt unworthy, very low, depressed and confused.
14	Very confused and upset.
15	Cannot remember. Although at the time I do recall my GP prescribed medication, oral injection, and my husband was encouraging me to take medication.
16	Very scared and alone.
17	I felt angry.
18	"Shit" Down as a .....felt the first time what it was like, to get an ear 'listen' a point in the right direction, even left alone, treatment.
19	Not helpful, GP just said to take the prescription and would feel better.
20	No response.
21	Well I relied on the GP to help.
22	Better.
23	Very disoriented.

**8 Did you see a GP?**

Yes 20  
No 2  
No response 1

**9 If yes, was your GP helpful?**

Yes 13  
No 6  
N/A (Did not see GP) 4  
(23NH) 1 participant said Yes + No (Helped bits but not fully)

**10 Which of the following services did you use?**

Day care services 1  
Hospital psychology unit 10  
Private therapy/counseling 4  
Social Services 3  
Other, please specify 7  
No response 2

**11 How do you feel about the services you received?  
(Please note any comments below on the next question.)**

Type of service offered and scale	Very satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied	Service was not used
Services	1	3	2	3	3	3
GP	3	1	4	4	4	1
Social Workers		1	2	1	1	9
Police		2	1			12
Hospital Staff		7	3		1	6
Nurses	1	4	5		1	7
Community Psychiatric Nurse		1	1	1		12
Doctors	2	1	2	5	1	7
Psychiatrist		3	4	2	1	7
Psycho-therapist		1	1	1	1	10
Chaplin/Faith Representative		1	2			12
Other, please Specify	2	1	1		1	5

**12 What more would you like to say about any of the services you used? Please provide as much information as possible. Where applicable please give details about how services were good/bad and what changes you would like to see made.**

1	I would have preferred for the hospital staff not to insist on parental involvement. GP & social workers - they were not being honest, they were trying to cover over things that I raised with them. The whole process was too long. 4 months prison, 17 months hospital, in Audrey House, 15 months. I do not accept the diagnosis still. To keep them off my back I take the medication.
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2	<p>G.P. could not help very much in the past. But has been more helpful recently. They now have a mental health worker attached to the surgery who I have been able to see. When my illness began I had to wait 18 months at least before I would receive treatments to I turned to private counselling and psycho-therapy. NHS staff were friendly and caring but the waiting time was frustrating.</p>
3	<p>The GP was really helpful - he had the same background as me, I was from Kenya and so was he. He spoke to me in my own language as well - so it was easier to explain how I felt. He did understand how I was feeling too. He realised how I was suffering. The doctor and medicine helped me get back on my feet and begin to cope again. The treatment was very good and helped me relax and put me back on my feet. After that I started working and the medicine helped me a lot. I went to the GP recently with an eye infection and the doctor did ask me if I'm ok because I looked down. I told him I had a death in the family, which was a big shock. He asked if I needed any help to get over this but I said no, I will be ok. So he did ask me if I can manage and offered help.</p>
4	<p>GPs: It took me a few times before I could get to see somebody. They just wanted to give me anti-depressants - at such a young age, I knew that wasn't right. Because I have an interest in holistic therapies and I had more of a knowledge about mental health, about emotional state, about physical state and they treat you like you haven't. I got knocked back about 3 or 4 times before I talked with a GP. They just want to prescribe you meds, that's always the issue, I just don't go now, I've found different coping mechanisms now. I had to literally force them into letting me see somebody. I knew I needed to speak to somebody.</p> <p>Psycho-therapist. I felt more confused I didn't feel like I got any help. I saw a child psychologist for about 4 years (it was not just about the bereavement) when all my family issues came out we had to carry on, because I was still feeling suicidal. Very dissatisfied, because if anything, it raised more issues for me than it solved.</p> <p>Social worker - Because I was stressed out, I saw the GP because I was wetting the bed and for some reason the doctor thought that my mum was hitting me and that's why I was wetting the bed. Then I was locked in a room with a woman, and I could hear my mum outside literally screaming to get me out. They were trying to get me away from my mum. I was asked all sorts of questions because they thought she was hitting me. It was very stressful. I think a lot is they have assumptions of people and family life. They assume that you're getting beaten. I think it's a stigma attached to being Asian, The doctor thought that because my mums disabled, therefore she must have been extremely depressed and that she was taking it out on me.</p> <p>And the first thing that woman asked me when I was locked in the room was 'how does your mum treat you and how does she deal with her disability?' So it wasn't about me, it was more about what she wanted to record. I didn't consent to anything like that, I didn't agree to anything. There's lots of assumptions. They assume you're Asian, and they assume that you're getting forced into doing something and then they assume you're being beaten. They don't realise that you're in this country, that you're not back home, you're going to have the same issues as a normal white person, its less an Asian thing. They see your colour before they see you. They don't look at you as being a normal person but having family issues. They make assumptions and they stick on your file but they don't get to know you as a person. I think that can mess you up quite a lot. I would never use the services again; I would never go to the doctors for this again, no never.</p>

5	My GP appreciated my situation and gave me the time off that I needed. Overall, I would say the service was unsatisfactory. My GP should have referred me to other professionals who could have helped me get through that experience. If someone comes in with mental health problems especially with no history of mental health problems before, the GP should give you time to recuperate and refer you to another professional for help, be that a counsellor or therapist.
6	Good services, very helpful, were good to talk to.
7	N/A
8	Very good service, helpful, easy to talk to
9	My GP was not caring and showed no compassion or understanding. He agreed to get a referral and I had to ask several times before he agreed. The process has taken way too long, over a year and a half and nothing has happened as yet. GPs should be more aware and more understanding about MH issues and the need for faster referrals.
10	I went to a private counsellor. She was very good, but gave me medication which caused unpleasant side effects, I had to change my medication several times before I settled on one which didn't have any immediate side effects. The medication made me put on weight I didn't like that at all I would have preferred alternative therapies.
11	My GP was informed by myself that I would like talking therapies because I was given medication, but then I went to my GP a week later and stated that tablets is not for me, I need adjustment.
12	Staff sat in their office and patients were left ignored- as almost as this was a big stigma. There needs to be more <u>communication</u> between professionals to professionals and patients to patients.
13	<p>Counsellor - I wasn't really happy about the service there; they put it down to a thyroid condition and told me to go back to the GP. So I felt like I was being yo-yoed a bit. I saw a counsellor and I wasn't really satisfied with him, I'd say dissatisfied. I know that there was a problem and I knew that I needed to do something about it. So I was after tools to help me do that. I didn't need to be told that 'there's nothing wrong with you', because how could somebody in one session say that there's nothing wrong with you without exploring things with me first. I didn't feel like I got the opportunity to really explore what the problems were. How could you say there's nothing wrong with a person unless you spent some time going through that therapy in the first place? I knew there was something not right with the way I was feeling and it was very unusual for me.</p> <p>GP –My experience was fairly straightforward, I went to the doctor, I was given a prescription, he referred me to a clinic, I went to the clinic, the counsellor said there's nothing wrong with you it sounds like a thyroid problem and go back to your GP. At this point I was in the process of being diagnosed with arthritis, so he put it down to all of that and said go back to your GP. I did my own thing then. I felt like I'm not going to get anywhere and I wanted to just start helping myself at that point. My first point of helping myself was going to the doctors, then going down the road that they put me on and seeing where I got to. I thought I might get a bit more out of going to that counselling session. When I came away on that session I didn't feel like I barely got anywhere even in terms of them forwarding me on to something where I knew I would get some positive help on how I felt. So I thought, just deal with this yourself, they're not going to help. So then I went back to family and the internet and self-help books and private counselling. I found my own journey – which was a lot better.</p> <p>Social worker – satisfied. I saw a Social Worker when I got diagnosed with my condition and I used social services from an occupational health point of view, they were helpful. Private counselling – satisfied. That was really good. I was almost like I was calling out for guidance because I was very confused, everything was over-exaggerated in my mind, I wasn't clear in</p>

	my thinking. It's almost like I needed somebody to sit down and help me with clarity. Everything I thought was wrong, everything I did was wrong, I was very self-conscious about everything. I think that's why that therapy really helped me, it helped me explore my issues, and it helped with my thinking and clarity. The doctor said I was depressed straightaway and prescribed me with anti-depressants. Actually I wasn't really happy about that, I wanted more than that. I didn't just want to take a pill. See, by this point, I was on loads of pills already and I didn't want to take another pill... but I did. I did for a bit, for a few weeks, but I just didn't like the effect they had on me, I didn't feel any better. I felt like I needed to do more personally myself.
14	There should be an easier transition between doctor and therapist.
15	I felt that there should have been a faith reprehensive, someone for me, and my family to talk to.
16	Would have liked counselling through GP. Rather than going private. So would like to see more alternative therapists.
17	Didn't like it when they changed my doctor. Some nurses and doctors were good others weren't. Didn't take me out for a walk when I wanted.
18	Referring to Doctor: I tried to contact a specialist in S.A.D based in Derby who I found from my own research, but was unable to contact him because I needed a referral from my GP and I wasn't fancying going back to my GP. I researched and I found a specialist. For a person to shout "help" and anybody in a position of health care to help that person. Not to have such stringent measures; so to access specialist help is made difficult.
19	At first I didn't know what or why I was taken to hospital. I knew that I was not feeling well but wasn't told of what I was suffering from. Then there was no halaal meals, no one of my cultural background except one doctor/ psychiatrist, but I did not have or see that doctor.
20	More home visits by lady doctor.
21	Something that I can understand it may be a video or tape, to help me understand what my problem is. More information for family and places to go so that if I cant tell family I know I can go to some to talk to.
22	There should be more options than drugs. GP should have more people dealing with mental health.
23	Helpful.

**13 Do you have any recommendations about how mental health services can be improved?**

1	To have more than a token Black face when being dealt with. The people that are dealing with your care.
2	(1) Waiting times <u>have</u> to be shortened. (2) G.P.s should discuss mental health with patients at least once or twice a year. (My G.P. never discussed this with me in the 10 years after my admission to hospital.) If my G.P. had discussed or reviewed this it could have prevented further worsening of depression. (3) Hospital environment was not suitable for my situation - alternative needs to be found for those suffering from depression.
3	G.P.s should have more time to be able to talk to patients about these matters and monitor their mental health too. As soon as someone suffers from depression they should have some serviced to counsel them straightaway.
4	The biggest thing I'd say is treating people as individuals. I know from my studies and my interests the biggest thing that is emphasised is individuality. Somebody may come from the same background and have the same upbringing but they've got their own personality, their own individuality and they'll have their own issues. They shouldn't look at you as statistics, they shouldn't look at you as a minority. I don't think GPs have heart and compassion, they have medical knowledge but they don't have emotional/psychological training to deal with patients with mental health issues. The GPs are the biggest problem; they stereotype you,

	put you into little boxes and make assumptions about you.
5	GPs need to have closer links with the Mental Health services that are available, and a referral system and a feedback system. So when the patient has seen the professional/counsellor should be able to feedback to the GP what the outcome was of their treatment.
6	More professional and everybody who work in the NHS should be properly trained for their job.
7	N/A
8	Have more professional more trained people in NHS
9	Faster referrals to counsellors. GPs should be more sensitive to mental health issues, I wish I could go to a different GP because mine is out of touch with my needs and culture. Perhaps a female doctor would be more receptive to women patients, I am not sure.
10	More alternatives to medication. I should not have had to go to private doctors the NHS is too slow.
11	Yes. More therapies.
12	More therapies for people. More information provided for people. More communication.
13	I think if I'd got the kind of response that I got at the university clinic from the counsellor and my GP, if the service was better and there was therapy available for me, then I probably wouldn't have had to go on and look for further help myself, and go to my family and look for some other sources myself. But at the same time I didn't mind that I did that because I found that it was a growing experience for me anyway. I think maybe there needs to be more options for therapy for people, through referral from your GP. When I went there I felt I wasn't given the opportunity to really express my problems. I just felt I was told to go back to your GP but I came to talk to a counsellor. They did talk to me, but not for very long. I can't remember much about what was said, but I remember him saying there's nothing wrong with you, it's down to your condition, and it's probably a thyroid problem. It's hard for me to give recommendations I think because I went and did things myself and I am quite happy with that, I am satisfied with my journey. But maybe it would've been nice if I went to see the doctor and I was looked after.
14	People should be given more time to explain how they feel; given the fact they will be confused.
15	Someone from my background and culture and visit me as I felt alone and isolated. Spent a lot of time crying because I missed my children and because my husband was from India he did not understand the .....? regulations of one hospital. In that he could take me out on day visits, so someone to have explained this to him in a culturally appropriate way.
16	Would like to see more free alternative therapies as well as complimentary therapies such as massage which are good for relaxation.
17	I would like permanent psychiatrist, as I was told I didn't need a psychiatrist. Should be more outdoor activity, like a walk, currently go once, but would like twice a week.
18	I think we are heading towards improvement anyway.
19	Have multicultural doctors and more information on the illness or depression in my language. And any other options or places to go to get support.
20	More lady doctors in mental health. More home visits. Less drugs prescription.
21	More of my own people should work or be told to work in this area.
22	More home visits by doctors etc. more venues to go to to talk, better places to visit.
23	They should have more professional people on NHS.

#### 14 Could you provide us with some more information?

1	Something like the DACMHA. They come and take you off the ward, you get a Caribbean meal. I found that beneficial. People with mental illness. Somewhere you could relax with your own constructive.
2	Waiting times could be shortened if more suitable forms of treatment are available. E.g. person suffering from depression should not be left with drug addicts and seriously mentally ill patients in hospital. Counselling, therapy and support in the community are more appropriate. More support, mental health workers in the community, available on the phone would help me stay well and not lead to worsening of my illness requiring more use on NHS services.
3	There should be a counselling service independent of the GP which you GP can refer you to, quickly. Your doctor should know what's happening as well.
4	In my particular case I should have been referred to see a counsellor because I went through a traumatic event, losing my father, so that counsellor should have seen me and fed-back to my GP and further treatment should have been based on that. Although when I had time off I felt better.
5	N/A
6	N/A
7	Have counsellor
8	Persons with mental health problems should be able to get family counselling as well as individual counselling because so many problems originate within the family or are complicated by family discord and misunderstandings.
9	Everyone should be aware of mental health issues and the possibility of being affected by them. Because you never know who or when it can affect you. If everyone- well people included- were more aware and sensitized then we could work to maintain our wellness before we become ill and prevent mental illness in some cases. So I guess work on prevention as well as cure.
10	Too much information on this question this question needs reducing.
11	Services should be developed tailored to needs in various languages for people and able to deal with their concerns. Some people are not understood and therefore misdiagnosed.
12	By training more people
13	Someone to be based at the hospital, so I could go to them when I needed. The environment was difficult, in hospital psychiatric unit because I was not familiar with where I could go or couldn't go.
14	The NHS as well as Social Services should provide more services available locally in the community. Bilingual mental health workers, possibly people with mental health experience such as ex service users. More health centres promoting well being and providing free services such as alternative therapies and complimentary therapies.
15	Not sure.
16	Now at this time of interview.....due to personal reasons.
17	Local community centres, libraries, schools and at GP surgery, multilingual support, train more people in our community to help us.
18	GP surgeries. More women groups. Park. Drop-in centre at GP.
19	Community association, mosques, schools, nurseries, DHSS (job centre), GP surgeries.
20	Home visits because they are better setting, more comfortable in my own surroundings. More doctors with other options than drugs. Talking helps and more places to go to relax for

	women.
21	Have counsellor in every GP if possible.

**15 What is you preferred language?**

English	10
English & Punjabi	4
Bengali	4
Shona	1
English/Patois	1
Punjabi	1
Nyanja	1
Punjabi & Mirpuri	1

**16 Were your language needs met by anyone in the health service?**

Yes 19

No 4      **If no, please explain:**

1	I spoke English but its not as good and I wasn't as able to understand everything. I wished there was someone in my language to explain.
2	I had my son explain
3	No I was not explained in my language, only family inheritance
4	Interpreters were available but I prefer that the doctors be able to communicate directly in my care the GP did but sometimes that the GP isn't there then that's a problem.

**17 Were you asked about any specific dietary needs**

Yes 3

No 14

N/A 6

**If Yes, please state how - give examples:**

Yes 1      "I think I was asked if I was vegetarian and appropriate meals were provided"

1	No, I do not remember. You asked for West Indian food but told not enough demand and too expensive.
2	At Kingsway hospital there was no choice of food, I was not asked about my dietary requirements.
3	No. When I went in then was a long time ago, this was never asked.
4	No. I knew that my drugs should be OK, but we didn't know if they are halaal.

**If no, please explain:**

**18 Were you asked about any specific religious/spiritual needs?**

Yes 6

No 13

N/A 4

**If Yes, How? Give examples:**

1	Yes. Just a form of exercise to tick a box, but not about my needs.
2	Yes asked if she would like an Asian therapist due to issue of black magic

3	Yes. No need
4	Yes, worship

**19 Were you asked about any specific religious/spiritual needs? If no, please explain:**

1	No one ask me they thought I was obviously different
2	No one ask if the drugs were halaal, and we didn't know. No one said that I would fall asleep and sometimes I miss my prayer
3	My drugs help me sleep, but sometimes I missing prayers and that makes me feel unwell.

**19 Do you have any other cultural needs and were you asked about them?**

Yes	4
No	19
No Response	1

(\* Total is 24 – one respondent answered yes **and** no to this question)

**20 Do you have any other comments about how culturally sensitive services were?**

Yes	7
No	14
No response	2

**21 Do you have any recommendations about how the service could be improved to meet you cultural needs?**

1	Hair care - down to individual nurses.  Food - Totally lacking. There should be Caribbean food on menu; there was one dish of stewed red peas and rice. City is better than Kingsway as they cater to many different cultures.
2	Asian doctors need to be trained not to ignore their own culture and the support they can give to Asian patients. In my experience Asian doctors seemed to ignore their own 'Asianess' & be more adamant & not listen to Asian patients.  They should have been of more help to me - I expected they would be but I was listened to only by White doctors. Asian doctors should receive training on their impact on patients of the same culture/appearance/ethnicity.
3	GP's should have access to information about comments that people have made, like this research, about cultural awareness. They should be trained using case studies, and people who have been through it, been through the bad experience, there should be more service users involved in training for doctors.
4	I know doctors can use interpreters but I don't like them. Sometimes they do not interpret in right way; they should be very careful how they are answering doctor's questions.
5	Professionals need to be able to have dialogue with patients in their own language, and be aware of their cultural differences and the traditions in that society so they can help them.
6	Not applicable
7	Not applicable
8	Left blank

9	I would prefer a female doctor personally. Sometimes I go to see the nurse instead of the doctor because they are so much more understanding and empathetic. So more female doctors should be available to treat women.
10	Yes I am from a Jamaican background and we tend to ignore and deny mental illness until the problem becomes unmanageable. Our community could use some education to raise awareness and reduce stigma of mental illness
11	N/A
12	Plus staff needs to be given training on these- This should be mandatory.
13	Left blank
14	N/A
15	It would have helped to have someone from my background and culture, as point of contact, as it would have helped me to understand what was happening to me.
16	No response
17	No
18	As above
19	No response
20	More things in my language, more women doctors more places to go and visit at home. Check if drugs are halaal and should be labelled.
21	As before more people who understand from my background.
22	No response
23	I am not sure but as I have said earlier more home visits, better language facility, they should know if the medication is halaal, and better options than just drugs and prescriptions, more support for family so they may understand the difficulties of being unwell.

**22 Were members of your family/community/friends aware of your situation?  
(Please tick all that apply)**

	Yes	No	No Response
Community	9	9	6
Family	20	3	0
Friends	15	6	2

**23 What was their reaction?**

1	The community was clique/closed. The family/ my mother intervened and the situation deteriorated. An old friend seemed to offer support.
2	Only my husband, reaction was shock at first, but supportive and accepting later.
3	Helpful, I spoke to my brother only because he was very close to me and could understand what was happening to me. My parents do not understand what depression means, they think it's not a real problem that I am making it up. Only my brother was helpful, he talked to me and explained what my tablets contained. He helped me learn yoga and explained how to change my lifestyle to make me feel better and be able to relax more. This is how I managed to help myself and recover.
4	Community: Oh it's nothing. Family: ignored not dealt with. Friends: could not understand it

5	N/A
6	Very supportive
7	Very upset
8	Very supportive
9	My family has been very supportive and encouraging
10	They (family) helped me financially when I needed to see a private therapist. They were very supportive besides this
11	Concerned, supportive
12	Relatives have become 'awkward' but I see that as their problem
13	No response
14	Very helpful
15	Family: They did not really understand my situation at the time, and just advised me all the time that I needed to be in hospital, it is only since my brother suffered with mental ill health that they have started to understand
16	At first they found it difficult, because they didn't understand or realize what was wrong with me, but afterwards they were very supportive
17	I should leave it, not very helpful. Family called me mental
18	Friends: Some supportive, others turn back on me. Family: Turn back on me. Community: Unforgiving. I don't think that any one of them were sympathetic or comprehensively understanding apart from a few friends
19	Helpful
20	They support me through all my life so far and I hope they continue as I am sure they will
21	They give me a lot of encouragement
22	Very supportive, didn't quite know how to help at the start but gradually they became supportive
23	Very supportive

**24 How helpful/ supportive were your:**

	Very Supportive	Somewhat Supportive	Neutral	Somewhat Unsupportive	Very Unsupportive	No Response
Family	15	3	0	1	3	1
Friends	9	3	5	1	2	3
Community	2	1	4	1	5	10

**25 Any other comments?**

1	No response
2	Family friends have always been there they also need to be supported
3	I need my family to feel that I am getting better so that I don't let my children down
4	N/A
5	No response
6	As above comment
7	Should be more information in schools about mental health
8	Mental health is a taboo subject which people don't like to talk about or acknowledge because there is a lot of stigma attached especially for women

9	At the time the initial episode of mental health, my families were not supportive or understanding as they did not understand. My husband although supportive, did not understand my mental ill health
10	Only family and friends knew about my illness
11	No response
12	Hard for family to understand. Who leave it to professionals who don't really understand?
13	No response
14	My parents knew right away because I always turn to them first, the rest of my family didn't find out until much later because I was concerned about the stigma and possible negativity
15	Family is so important in the recovery process. They can be an extremely valuable resource in helping you to manage symptoms
16	No response
17	N/A
18	There should be an awareness within the community
19	I didn't really discuss this with anybody other than my GP because I didn't think that family would understand or appreciate what I was going through because of the way they were brought up and lack of knowledge of mental health issues
20	Not much involvement
21	I did not speak to anyone in my community because they were not people like me. I was quite advanced and independent and all the other Indians in derby at that time were not like me, so I did not feel I could talk to them. It was better for me to talk to my GP. Also, I did not talk to my parents or husband because they feel that depression is not a real illness you are just weak and making it up
21	I did not discuss my situation with my family, only my husband knew- no one else, not family or friends. I was embarrassed, I thought everyone would think less of me, and also I wanted to shut out my illness and not accept it- it was easier to do this if hardly anyone knew about it. It made the illness less real; I did not want to be seen as 'mad' – that's what I used to think being mentally ill meant
22	No response

**26 How often did your family and friends visit you while you were in hospital?**

	Daily	Weekly	Monthly	Never	Other (specify)	No response
Family	11	3	0	1	0	9
Friends	1	4	1	5	0	12

**27 Did you want your family/friends to visit: More, Less, No Difference, Not at all (Please Explain why)**

	More	Less	No Difference	Not at all	No response
Family	5	0	7	2	9
Friends	4	0	7	1	10

**28 Do you have regular support from a carer(s) If yes, how many?**

Yes 6  
 How many 3, 3, 1  
 No 17

**29 If yes, is your primary carer:**

Family 6  
 Friend 1  
 Other 1 (CPN)  
 No carer 16

**30 Do you have your own informal support networks?**

Yes 19  
 No 7  
 No Response 2

**31 Apart from the NHS, what mental health services are available for people with mental health problems/issues in your community that you are aware of? Please list.**

Don't Know 4  
 None 5  
 No response or N/A 7

**Other responses:**

1	GP has a mental health worker you can see and receive support from. DMN have staff you can talk to if necessary and can provide links to other services. I think there are some local groups but I am not sure who they are or what service they provide.
2	I mainly know about groups/services for domestic violence because its an Asian area that's what's mainly dealt with. If there is anything else for mental health I haven't seen it, and I keep my eyes open.
3	There may be some voluntary community groups that provide help.
4	Private Doctors/Psychiatrists
5	Hadhari Project. Carers' Project.
6	I attend the Asian Women's group from the CMHT, and I an aware there is a group for Asian women every Tuesday at the Indian Community Centre.
7	MIND. Rosehill centre- MIND

**32 Are there any other types of mental health services you would like to see in the community? Yes 19**

No 2  
 No Response 5

**Examples:**

1	A Drop in/Day care centre
2	Counselling services in the community - at least one person in each ward. These should be free and confidential and link in to your GP if the patient wishes. These services should be clearly signposted as places you can go to if you are nearing crisis. I think this would prevent admissions to hospitals.

	I think faith centres should talk more about mental health in their communities and be more open about this, to reduce stigma and encourage people to use community support and to help them.
3	I would like them to have somewhere nearby, like in Normanton, where somebody can get help quickly and not to waste months and months. There should be somewhere to go to talk, or maybe they can make a home visit. There should be a quicker, fast service and they should be able to speak in their own language.
4	<p>I don't think they help anymore personally, but there are people out there that do respond to counseling. There should be more coaching on life skills, giving you tools to deal with life issues and it should be something that's very obvious – easy to see and find. It should be run by trained professionals (not people who are just going to the 'next project') and they should be of mixed ethnicity.</p> <p>They shouldn't use an Asian name, it should be something that is relevant in all cultures – almost like a shoulder! Also there needs to be a telephone helpline, something like the Samaritans but with an option to book in to see them also afterwards. This can be run by the NHS or a private organization (private tends to have better standards). There should be standards, it should be clear what they're there for – not just filling in job applications and other forms. There should be a precise and concise service to meet mental health needs only.</p>
5	Yes. Maybe community based counselling for women. Perhaps there could be counsellors at some of the local community centres, that way people could go to someone from their own group who understands their cultural, religious and ethnic background.
6	Yes. Support groups for young women with mental health issues, like alcoholics anonymous but for mental health sufferers where you could go to regular meetings and have mentors or "buddies" or just drop in to meetings on a needs basis.
7	A Black and Asian supported housing project.
8	It's very hard to think about it as 'out there' because I tend to kind of just deal with it myself. I don't rely on 'out there' anymore. So I don't really even look to see if there are any services out there. I suppose I do in terms of the bookshop, so that could be a service. Things like self-help services, things like 'knowledge is king', that's a book place based on self-help books. So may a drop-in centre where you could find that sort of information.
9	People should be allowed to see specialist without delay.
10	More groups such as the Asian women's group that you can go to sit and talk, but do activities and go places, and learn new skills, because it gives you confidence.
11	More health centres and community development workers.
12	Should go to temples to explain about mental health.
13	None at the moment that I can think of. Can you let me know later?
14	People from my own community being encouraged to train in this area. Start with training from boys and girls.
15	Something in the park.
16	Yes more tapes and video maybe programme on community channel. And centres with people speaking my language.
17	More specialists in community centres, places of worship, local shops and GPs should have info and drop in home sessions.

### 33 Is there anything else you would like to say about what would have helped you?

1	To have not been held in the system for as long as I was. I felt that a lot of the things that I needed to do in order to take care of myself I was able to do.
2	Follow on help - appropriate support - once I left hospital. I had one appointment a little while after I left hospital to see how I was doing and I lied that I was well to avoid going back to hospital. No-one spoke to me or helped be work through my problems in hospital - I was left to wander around, being offered drugs by other patients, staff did not seem interested in me. The whole experience was very isolating and scary and I would avoid ever going to hospital again. Depressed patients should automatically get counselling when they leave hospital - straightaway.
3	It would have helped me if someone came to my home to talk to me about this, I would have used this sort of service.
4	Respect for individuals, treating everyone as individuals. A professional service – not a conveyor belt one in one out. Counsellors have about 15 minutes between appointments which is not enough to switch off and restart. Many times I could tell my counsellor had not recovered from the last session.
5	A lot of people see their GPs so its important that GPs have links to other services, even voluntary services, they should have leaflets or information to give to patients.
6	People should be encouraged to see a doctor as soon they don't understand about their thinking.
7	N/A
8	Left blank
9	Family counselling
10	I shouldn't have to pay for private service because NHS is so slow and there is too much procedure and red tape for a person in crisis to have to wait for.
11	No response.
12	No response.
13	I am satisfied with how things went for me. If things didn't go the way they went I wouldn't have going in the direction I went in and found the university clinic, I wouldn't have gone my own way and learned things about myself. Even though I didn't find it helpful when the doctor offered me a pill but maybe there was a good outcome at the end of the day. But maybe support at the beginning would have got me on the same road, but with support where I expected to get that support.
14	It's hard to know what can help you when you have a confused mind.
15	Just do not want other people to go through what I went through, in terms of explaining and understanding medication.
16	More talks raising awareness at schools, confidence building courses.
17	No.
18	Direct access to specialist. Awareness of self help programmes available to sufferers i.e. WRAP
19	More information in languages and more programmes to show or tell us more about mental health more on media, any newsletter from the community would be good
20	Don't know.

21	Something for my family if they were or needed someone.
22	Less drugs, more talking to someone.
23	No response.

**34 Were you given medication?**

Yes	21
No	1
No Response	2

**35 Were you informed about the medication?**

Yes	10
No	11
No Response	2

**36 Did you understand the information provided?**

Yes	9
No	10
No Response	4

**37 What information were you given about your medication?**

1	The medication given was to treat psychosis. The dosage was administered by nurses. Been on 4 different medications. Asked to come off Olanzapine because of weight gain.
2	I don't remember being told anything in hospital about the medication I was given. Since then my GP has given me medication and has been clear about side effects and doses and how it would help me.
3	GP told me what depression means. He did not explain much about side effects but he did say that when I stop the tablets I need to stop slowly, bit at a time. I did slowly read the leaflet about side effects slowly.
4	When I was told about medication I said I don't want drugs or happy pills. Oh they're not, they'll make you calmer and will help you deal with things. How can a pill help you deal with things, does it talk to you, does it ask how you're feeling, does it befriend you? No, it goes in your stomach and dissolves and comes out the other end.
5	The medication was just painkillers, so it was very basic treatment really.
6	They explain everything to me
7	N/A
8	Bad reaction to medicine
9	N/A
10	I was told about some of the side effects but not the probability of these occurring. I agreed but I didn't think it would apply to me. I had lots of problems with side effects.
11	I was informed about the drug, dose, and side effects short term medication.
12	No information
13	They did tell me that it would take a few weeks for them to take effect. I read all the information about it at home anyway.

14	N/A
15	I was given no information about medication, no dosage, no advice on side effects, nothing all I was told was you will be alright just take this medicine. This was previously, but I understand now.
16	What it was for, dosage and when to take.
17	N/A
18	They were standard Anti Depressants which few friends told me not to take and to ....
19	When to have it. That's it.
20	When to take them, if I didn't take them then what may happen, e.g. feel ill.
21	Take at what time
22	When to take and dosage
23	Bad reaction to medication. Took two months to withdraw from it.

**38 Did you consent?**

Yes 20  
 No 1  
 No Response or N/A 2

**39 If yes, how did you give your consent?**

Written 2  
 Verbal 15  
 N/A (no consent) 3  
 No Response 3

**40 Were you told about possible side effects?**

Yes 8  
 No 13  
 No Response 2

**41 Were you told about alternative therapies?**

Yes 5  
 No 17  
 No response or N/A 1

**42 Have you ever been hospitalized?**

Yes 10  
 No 10  
 No Response 3

**43 If yes, were you ever:**

Isolated 1  
 Segregated 0  
 Discriminated against due to race or colour of our skin 1  
 Other, please specify: 3  
 (Don't Know. People treated me differently. Didn't know I was not well.)  
 N/A or No Response 18

**44 While in hospital how involved were you in the planning/design of your care plan?**

Very Involved 0  
 Somewhat involved 2  
 Neutral 2

Rarely involved 0  
 Not at all involved 10  
 No Response or N/A 9

**45 While in hospital how involved was your carer in the planning/design of your care plan?**

Very Involved 0  
 Somewhat involved 3  
 Neutral 7  
 Rarely involved 0  
 Not at all involved 3  
 No Response or N/A 10

**46 Did you agree with it?**

Yes 7  
 No 5  
 No Response 11

**47 Did you understand it?**

Yes 5  
 No 4  
 No Response 14

**48 After you were discharged from hospital what follow up support was made available to you?**

None at all 3  
 Can't remember 2  
 N/A or No response 14

**Other responses:**

1	Visits by a social worker and support workers. Also a CPN and trainee social worker. (After discharge from Derby City Hospital.)
2	None whatsoever - my GP never even asked me about my stay in hospital or my mental health - until I mentioned it recently. I had one follow-up appointment with a doctor.
3	Just my family and my therapist.
4	I had a CPN, and sometimes a social worker would visit me
5	Don't know

**49 Do you have a Community Psychiatric Nurse?**

Yes 2  
 No 13  
 No Response 8

**50 If yes, how helpful is she/he?**

Very Helpful 1  
 Somewhat Helpful 0  
 Neutral 4

Not very helpful 1  
 Not at all helpful 3  
 No Response 14

**51 Were you allowed at any time during your stay to leave the hospital unescorted?**

Yes 3  
 No 10  
 No Response 10

**52 How were you treated by doctors?**

	Very Bad 1	2	3	Neutral 4	5	6	Very Good 7	No Response
When you were on the ward	1	0	0	8	1	1	4	4
When you returned home	0	1	0	5	0	3	2	8

**53 What improvements do you want to see in the delivery of mental health services? Please list and explain.**

1	<p>A day care/drop-in centre for Afro-Caribbean people.</p> <p>Throughout my care I have wanted to have more independence and feel that I have not been listened to. Hospital should have taken on board that I did not want visits from my mother. Would prefer a Black CPN. Would like to limit the time/intervention of CPN - more independence.</p>
2	<p>Appropriate services for each illness - depressed/suicidal patients should not necessarily be mixed with other patients in hospital.</p> <p>There should always be regular follow-on support and review of these patients - leading to alternative therapies or treatment if necessary.</p> <p>GPs should review mental health with patients who have been hospitalised or diagnosed with a mental illness at least annually - with the patients consent.</p> <p>Patients should be asked about their hospital stay after they leave to review the service they received, to give feedback at a reasonable time and to be able to make changes/improvements.</p>
3	<p>There should be some good organisation independent of the GP where someone can go for counselling. I can think of many people now who need this but they don't know anywhere to go.</p> <p>This should be a quick service and be able to speak in the person's own language. Also they should put leaflets through the door about this service in different languages,</p>

	<p>especially for older people who can't get out to find out about these things.</p> <p>Many people don't realise they're suffering from depression, the doctor should tell them and offer some counselling and tell them where to get help.</p>
4	As mentioned before just that the various agencies work together.
5	The community should be informed about these problems. It should start from schools.
6	N/A
7	<p>Have more professional counsellor.</p> <p>From cleaners everybody should be trained for what they do.</p>
8	N/A
9	More education/ awareness of the stigma and cultural issues that west Indian community has with mental health services could engage more with the black community as a whole and reach out to those who are well also to improve prevention and wellness instead of only focusing on recovery and managing illness and symptoms.
10	No response.
11	Support for family/carers more information.
12	I was sent to a counsellor and I think that there should be more help as psycho-therapy rather than counselling. I don't know if someone listening would really give you any tools for coping with depression. I found I got that from cognitive behavioural therapy and from psycho-therapy. So I think there needs to be some sort of evaluation done to find out what kind of therapy is needed, even at the GP stage or by the counsellor. Maybe that was the whole point of the meeting I had with the counsellor and it just didn't work for me.
13	Less time between GP and specialist
14	I had mainly Asian doctors, but none of them explained anything to me as an Asian woman or my husband, I felt maybe because they felt or assumed we already understand, so possibly better training for staff.
15	More places where they do free counselling apart from the GP. More talks and seminars to raise awareness of mental health.
16	More community nurses on the ward.
17	Someone suffering should be able to say at any service "I need help" and appointment made to discuss the condition with a very well informed MH Professional(Role not yet defined) One to one basis who can then identify problems and suggest (help to access services- programmes.
18	More other options at GP than being given tablets
19	Help people understand about depression etc. More info at home in language, more lady doctors.

20	More programmes and tapes/videos to watch. More people trained up who speak my language and know about mental health.
21	More home visits by specialist doctors
22	Community should be educated through the media. Signpost placed in market place, again by advertising.

**54 How do you feel about yourself now?**

1	Disoriented
2	I'm better now, I feel healthier but still take my prescriptions, but I do feel tired and some days I feel unwell. I feel good today.
3	Good.
4	Good. I feel better but some times I feel very tired
5	Well
6	Ok. Knowledge is power and my ability to research my condition and symptoms and to understand and take charge of these and related issues has allowed me to resolve these issues and access self help programs.
7	I am Ok now
8	I understand my illness a bit better now and have developed coping strategies to manage my illness.
9	I feel alright, much better, a little more confident
10	I still have times I feel dizzy
11	No response
12	I learnt so much from the experience
13	Very positive, chilled and relaxed
14	I feel better now, but I still go to therapy. I have very little faith in the NHS and couldn't rely on services to help me in time
15	No response
16	No response
17	Feel better
18	Better
19	Fine
20	Stronger but I feel disappointed that I had to go through so much to get to this point. It took me 10 years.
21	I feel very well, very confident, I'm alright. If I have any problems again I have my children and talk to my doctor and I know where to go now for help.

22	I still suffer from depression but realize I have to help myself more than rely on doctors. I have been able to ask my GP for support now and finally been given some help this year after 14 years of illness.
23	I'm well enough to look after myself and my place. But I don't feel well enough to look for work right now.

## **Section 7. 4: Appendix 4 – Carers Data Results**

**Section 1. Brief**

**Section 2. Results Questions 55 to 67**

**Section 3. Core Data Results 1.1 to 1.10**

### **1. Brief**

**15 Respondents**

**First Contact:**

<b>Contact</b>	<b>Number</b>
GP	9
Residence Manager	3
Family	1
Ambulance/NHS	2
<b>TOTAL</b>	<b>15</b>

Of the 9 respondents who first contacted the GP for help 4 found the GP to be “not very helpful”. 3 of these rated the GP as “somewhat helpful”, and 2 said the GP was “very helpful.”

### **Additional Support:**

Respondents indicated that they received the following types of support:

- CPN (Community Psychiatric Nurse)
- Induction courses within the residence home
- Self help, research
- Advice from friends

### **Improvements/Recommendations:**

Respondents indicated the need for the following improvements:

- **Outreach**  
1 respondent indicated the need for more outreach efforts particularly in the black community.
- **Training/Culture**  
2 respondents felt there was a need for more training of doctors particularly training Asian doctors to be more aware/sensitive to the cultural needs of Asian carers and service users.
- **Communication/Information**  
3 respondents felt that there was a need for more information to be made available both to carers and the general public about mental health. 2 of these respondents suggested that

there should be more focus on spreading information through the media, advertising and public service announcements.

- **Personalised service / Therapy**

6 respondents mentioned the need for services to be more tailored to the individual needs of each case. More specifically, 4 of these respondents indicated that there was a need for more specialised therapy services for specific groups rather than relying solely on medical intervention to manage illness.

1 respondent also stated that there should be a dedicated mental health services located at the GP's surgery and within the community.

1 respondent also suggested that there should be more talk therapy as an alternative to, or to compliment medication.

- **Partnership/Networking**

Respondents suggested more partnership/networking within the services would improve service delivery, and that the carer should be fully involved in all aspects of the partnership as they spend the most time with the service user.

- **Accommodation/Facilities**

Respondents also mentioned the need for more accommodation and sheltered housing options for service users with appropriate supervision and security.

- **Recovery**

1 respondent mentioned that there should be more focus on recovery and not just managing illness.

- **Support**

7 respondents mentioned the need for more support in general.

5 of these respondents specifically mentioned the need for more financial support for carers.

Respondents also mentioned the need for more support in the form of counselling and advice for carers, in the form of:

- BME carers network and support groups for carers
- More BME support workers
- Hour helpline

Respondents suggested the following forums for intervention services:

- Local Associations
- Schools
- GP surgery (dedicated psychologists)
- Drop in centres
- Universities

## **Section 7. 4: Appendix 4 – Carers Data Results**

continued

### **Section 2. Results Questions 55 to 67**

#### **Q55**

When the person you are caring for first became ill, who or what service did you contact?

GP	9
Manager	1
GP and Manager	2
Family	1
Family and manager	1
GP and CPN	1
<b>Total</b>	<b>15</b>

#### **Q56**

How did you know about who to contact?

Knew from GP	5
Followed procedure	5
Through family	3
Did not know who to contact	1
Left blank	1
<b>Total</b>	<b>15</b>

#### **Q57**

How helpful were they? (first person contacted)

Very helpful	5
Somewhat helpful	4
Neutral	1
Not very helpful	3
Not at all helpful	1
Left blank	1
<b>Total</b>	<b>15</b>

Of the 9 respondents who first contacted the GP for help, 4 found the GP to be “not very helpful”. 3 of these rated the GP as “somewhat helpful”, and 2 said the GP was “very helpful.”

**Q58**

As a carer how much did you understand about the illness of the person you are caring for?

**Key:** From the scale of 1 – 7 where 1 means no understanding at all and 7 means very good understanding.

At the onset	During treatment/hospitalisation	Now	Understanding:
1	6	7	Increased greatly during treatment
3	5	7	Increased substantially
6	5	6	Stayed about the same
5	4	5	Stayed about the same
2	4	4	Increased a little
4	7	7	Increased a little
Blank	4	Blank	
2	4	7	Increased substantially
1	2	3	Increased slightly
1	Blank	Blank	
6	6	7	Stayed about the same
1	2	3	Increased slightly
3	4	5	Increased slightly
2	3	6	Increased substantially
Blank	4	Blank	

**Q59**

As a carer, did the Mental Health Services offer you any additional support?

Yes 4 27%

No 11 73%

**Q60**

If yes, please explain what additional help was given?

Response given	Help given	Response to Q59
First when I called the ambulance was there in time. When we get to hospital they were able to attend to the problem in time and had to treat the person very quickly.	Medical attention	Yes
GP referred to Counselling	Counselling	Yes
CPN	CPN	Yes
They offered me some courses such as induction	training	Yes

Self help, research and advice from friends	Respondent helped themselves	No
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**Q61**

How do you feel about Mental Health Services in Derby now?

Feeling:	Rating no:	No of responses given against each rating:
Very bad	1	1
	2	3
	3	2
Neutral	4	4
	5	2
	6	1
Very good	7	2
	<b>Total:</b>	<b>15</b>

**Q62**

What improvements do you want to see in the delivery of mental health services? Please list and explain

Responses:
<p>I would like help with more outreach. Want Black Carer- Black mental health outreach who can visit in the home and reassure her.</p> <p>A drop-in centre where you can spend a few hours. Somewhere were young people with mental illness meet, with activities - day out.</p> <p>More training is needed</p>
<p>There has to be more information in public places.</p> <p>More adverts are needed through the media</p>
<p>Offer of therapy solutions not just medical physiological interventions.</p> <p>More specialised services for specific groups</p>
<p>More support for BME Communities</p> <p>More communication</p>

**Q62 continued**

What improvements do you want to see in the delivery of mental health services? Please list and explain

Definitely there should be a support network in place between the professionals, the carer and the patient. Because each profession has their own role to play in supporting the patient, but so does the carer, and it's the carer that with the patient most amount of time. And although they have no professional background they are most aware of the patients needs and it's important that they are included in the treatment and care of the patient.

There should be better in house facilities for patients to use, such as accommodation, resources that the patient can use. More resources targeted towards their recovery. Not just a case of going to hospital and then going back to where they're living.

Half the time they're wandering the street. Professionals should visit patients at home more in this case. This person was homeless and rented accommodation was just not suitable. He was very vulnerable and people did take advantage of him, he really needed a place such as sheltered housing then be supervised. Professionals could come in as and when they needed to check on him and provide medication and liase with each other. He didn't need hospital, he was able to live relatively independently he just needed supervision.

More support and help for carers

The carers need support and security in time of crises. Arrange activities for them to feel free from their illness

I want them to disseminate more they have to the workers

Better information in my language and more access to people who are specialist

Different way to access specialist, why do we not have a psychiatrist/psychotherapist. Drop in centre at our GP's, why do we have to go to GP first, we need dedicated centres both in NHS and outside

No alternative avenues were explored by our GP. There needs to be more talk therapy available. Drop in sessions both at local but also 'in home', drop in sessions by psychotherapy. More intervention through media, local associations, schools, GP dedicated psychotherapist, more drop in centres

There should be support or aftercare after each counselling session. There needs to be more home visits-services delivered in the home. It would be good to see disabled people giving advice, support and counselling. Asian counsellors should have an awareness of all aspects of their culture and have professional standards

**Q63**

What particular support would you like to see for carers?

<b>Responses:</b>
It has been a strain for me, carers need help as well, its stressful and need some support.
You need courage and more support
Carers need more training and courses
More support from doctor and advice on who to contact
Groups, on steering boards, at conferences, involved in tasking groups
Support groups and more support workers from BME communities
Greater financial support because of the time they donate to caring
Someone to explain illness and how to better cope with it. More financial help too
The carers need to be well looked after
They should be given extra allowances and support in the form of counselling
More networks for people to share particularly in my community or society, things should be available locally at school and university and at GPs
Financial, support networking like Sure Start for mums but for mental health
Support Networks and financial and complementary support, again more media orientated programme literature and audio visual programme
More training of people
More advice about coping mechanisms. Perhaps a 24hr helpline providing advice and coping mechanisms and they should be able to book an appointment for them to see you also if needed. This can be volunteering or NHS, but needs to have professional standards. Support group-but not only with other carers also with people outside the area-sometimes you want to speak to someone who isn't immersed in the problem.

**Q64**

Is there anyone in your family who works in the Mental Health service?

Response	Number	%	Comments
Yes	3	20%	One stated 'support worker'
No	12	80%	
<b>Total</b>	<b>15</b>		

**Q65**

Would you be interested in receiving information about becoming a care/advocate?

Response	Number	%
Yes	7	46.5%
No	7	46.5%
Blank	1	7%
<b>Total</b>	<b>15</b>	

**Q66**

Would you like to provide support for people coming back into the community?

Response	Number	%
Yes	8	53
No	6	40
Blank	1	7%
<b>Total</b>	<b>15</b>	

**Q67**

Would you like to be involved in how Mental Health Services are run?

Response	Number	%
Yes	10	66.5%
No	4	26.5%
Blank	1	7%
<b>Total</b>	<b>15</b>	

**Section 3. CARERS CORE DATA RESULTS****1.1 Age last birthday:**

<b>Age</b>	<b>Number</b>
15 or under	0
16 - 18	0
19 - 21	1
22 - 24	0
25 - 29	4
30 - 39	7
40 - 49	2
50+	1
<b>Total</b>	<b>15</b>

**1.2 Gender:**

Male	7
Female	8
Transgendered or transsexual	0
<b>Total</b>	<b>15</b>

**1.3 Ethnicity**

Black - African	3
Black - Caribbean	6
Asian - Indian	2
Asian - Pakistani	2
Asian - Bangladeshi	2
<b>Total</b>	<b>15</b>

**1.4 Were you born in the UK?**

Yes	6
No	9
<b>Total</b>	<b>15</b>

**If no, how long have you lived here?**

Less than a year	0
1 - 5 years	5
6 - 10 years	1
11 years or more	3
<b>Total</b>	<b>9</b>

**1.5 Are you a?**

British Citizen	9
Refugee	2
Asylum Seeker	2
Other - Student	2
<b>Total</b>	<b>15</b>

**1.6 What is your first language?**

<b>Spoken</b>		<b>Written</b>	
English	10	English	10
Arabic	1	Arabic	1
Shona	3	English & Shona	2
Urdu/Punjabi	1	English/Urdu	1
		Blank	1
<b>Total</b>	<b>15</b>	<b>Total</b>	<b>15</b>

**1.7 Which languages are you fluent in?**

<b>Spoken</b>		<b>Written</b>	
English	5		7
Shona & English	3	English	3
Urdu/Punjabi	1	Shona & English	2
English & Bengali	2	English/Urdu	1
English & Punjabi	1	English & Bengali	
English, Punjabi, Urdu, Hindi	1		
English, Urdu, Punjabi, Mirpuri	1		
Blank	1	Blank	2
<b>Total</b>	<b>15</b>	<b>Total</b>	<b>15</b>

### 1.8 What is your religion?

Christianity	7
Muslim	5
Sikh	1
None	2
<b>Total</b>	<b>15</b>

### 1.9 Sexuality:

Heterosexual or straight	13
Blank	2
<b>Total</b>	<b>15</b>

### 1.10 Do you have a disability?

Yes	2	1 - Manic Depression, 1 - Dyslexia
No	13	
<b>Total</b>	<b>15</b>	

## **Section 7.5 Appendix 5: Mental Health Services Data/Brief**

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### **Slow referrals / services:**

- 8 Respondents complained that the wait for a referral was too long.
- Respondents mentioned waiting over 18 months.
- 7 Respondents failed to get a referral from the GP after a long wait.
- 5 respondents eventually sought private counselling/psychiatrist.. Although respondents generally rated their experience with private service as positive, some stated that they would have preferred to have had the referral in the first place. 1 respondent did eventually get a referral but sought private counselling due to dissatisfaction with NHS counselling services
- Other respondents complained of becoming frustrated with long waits and slow service but in general (but did not specifically mention referrals).

### **Recommendations include:**

- a) Counselling independent of GP with quick access.
- b) Counsellors attached to GPs surgery
- c) Family counselling to compliment individual counselling for a more holistic approach to recovery.
- d) More help as psycho-therapy and cognitive behavioural therapy rather than counselling.

### **Communication and Language:**

- 7 respondents indicated that there was a lack of communication between them and the GP, hospital staff and other health care professionals.
- Respondents attributed this breakdown in communication to:
  - a. Staff not listening to/ignoring patients
  - b. Staff not respecting patients wishes to keep family away
  - c. Staff not explaining to patients and their families the details of their illnesses
  - d. No faith representative on staff to talk to patients and their family
  - e. Not enough material in respondents language
  - f. Needing someone outside of the family to talk to about their illness.
  - g. GP not monitoring the recovery of patients, not talking them at regular intervals about their mental health.
  - h. No feedback or communication between counsellor and GP.
  - i. Patients needing more time to talk to doctors about their problems.
  - j. Misdiagnosis as a result of misunderstanding.
- One respondent related a positive experience of communication, stating that having a GP who spoke his/her language was very helpful and that the GP really understands how he / she feels.

### **Recommendations made on this topic:**

- a. Phone access to emergency help to avoid crisis or worsening of conditions.
- b. Alternative materials such as videos and tapes in their language which explain their illness.
- c. Services should better adapt to the language needs of the service users.- e.g. local community bi-lingual mental health workers

## **Section 7.5 Appendix 5: Mental Health Services Data/Brief** continued

### **Trust**

- 3 respondents expressed a lack of trust in GPs and/or Social workers;
- 2 stated that they feel their GP is not caring or understanding.

### **Recommendations made:**

Mental Health staff/workers who are ex-service users/ carers

### **Drugs and alternative therapy:**

- 7 Respondents indicated that they did not want to rely solely on medication to manage their illness. They stated that they would like to have more alternative therapies available to them.
- One respondent asked his/her GP for alternatives but this request was not dealt with.

### **Recommendations made:**

- a) More focus on wellness and prevention in the community as a whole rather than focus solely on managing illnesses, e.g. health centres promoting well being
- b) Free services such as alternative and complimentary therapies

### **Culture/Religion/Gender:**

- 2 respondents indicated that they would prefer gender specific GP.(female)
- 2 respondents indicated that there were no Halaal meals/ or medication available to them in hospital.

### **Recommendations made:**

Service users recommended the following improvements in this area:

- a) More services like DACHMA which take patients out occasionally for ethnic meals.
- b) Day care or drop in centres for people from specific ethnic/cultural groups
- c) More women's support groups in the community

### **Diverse/Representative Staff:**

- 4 respondents mentioned that they would like to see more representative staff in the NHS. (Particularly someone from their cultural background or ethnicity)
- Some felt that this deficiency in staff leads to feelings of isolation and loneliness in patients.

### **Training and Professionalism:**

- 5 respondents felt there needs to be an improvement in the level of training and professionalism of staff.
- 1 respondent referred specifically to emotional/psychological training for GP's. And sensitising Asian GP's about being less dismissive towards Asian patients.

### Positive experiences:

- 4 respondents rated their experiences as positive, describing hospital staff and GP as friendly, helpful, and understanding.
- 2 respondents noted an improvement in service over the years.
- 1 respondent specifically mentioned that there is a MH worker attached to the GP surgery.

### Other:

- 2 respondents felt that the hospital environment was unpleasant and not conducive to recovery.
- 1 respondent referred specially to patients with milder mental health issues such as depression being treated in the same place as drug addicts and “seriously ill” patients.
- 3 respondents mentioned the need for more places to go within the community to talk and get support.

### Recommendation of locations where support could be offered:

- Community centres
- Libraries
- Schools
- GP surgery
- Park
- Drop in centres
- Community Associations
- Mosques
- Nurseries
- DHSS (job centre)
- Home visits
- Women’s centres

First realised they had mental health issue	Number
Over 18 months	16
9-12 months	3
6-9 months	2
3-6 months	1
0-3 months	1
<b>TOTAL</b>	<b>23</b>

- (All respondents answered **yes** to having experience with MH services)

## Section 7.6 Appendix 6: Family and Community Brief

Respondents who had some form of Support	14
Respondents who said they had no support	7
N/A or No response	2
<b>Total number of respondents</b>	<b>23</b>

Of the 23 Respondents:

- 10 mentioned family as their main source of support, of these 10,
- 2 specifically mention their spouse/partner.
- 2 mentioned friends as their main support.

**Family:** Respondents mentioned trips out with their family and being with their “own people” as sources of comfort during their illness.

**Family’s understanding of mental health:** Three respondents indicated that support from their families had increased after their families began to better understand their illness.

**Talking to someone:** Two respondents mentioned that being able to talk to their family during their illness was beneficial. And one respondent stated that they felt not being able to talk to their family made coping with their illness more difficult. One respondent mentioned being able to talk to his/her doctor as a source of support.

**Other:** One respondent indicated that family support was beneficial because they provide a “place to stay”. One respondent cited other coping mechanisms such as meditation and yoga besides friends and family as support.

**Reasons for not wanting visitation:** 2 Respondents indicated that they didn’t want to be visited by family because of conflict or discord in their relationships. Both respondents indicated that the hospital staff and/or therapists ignored their requests to stop family from visiting.

**Family’s understanding of mental illness:** 1 respondent who was satisfied with visitation associated this with their family having a better understanding of their mental illness. 1 respondent who stated that they would have liked to be visited more by family attributed the absence of their family to a lack of understanding of mental illness.

<b>Visitation while hospitalised:</b>	Family	Friends
Respondents who wanted more visitation	5	4
Respondents who were satisfied with visitation	7	7
Respondents who wanted less visitation	0	0
Respondents who wanted no visitation at all	2	1
N/A or No response	7	9
<b>Total number of respondents</b>	<b>21</b>	<b>21</b>

## **Section 7.7 Appendix 7: Support Brief**

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### **Of the 23 respondents:**

- 13 said they had support - of those 10 had support from family, stating that family were 'my own people' and that family were understanding of their mental health issues.
- 4 respondents mentioned the support of their friends.
- 7 said that they had no support
- 2 found support in self-help and yoga.

When asked what services are available in their community that they are aware of, the following answers were given:

- 7 respondents mentioned local groups or services through their GP.
- 4 did not know of any services
- 5 stated that there were no services in their area.
- 1 mentioned private doctors.
- 6 did not answer the question.

### **Services in the community:**

- 8 respondents did not give suggestions for services they would like to see in the community.
- 15, there was strong opinion for services in the local community in their own languages.

Some suggested Health centres and specialists or Community Development Workers who could help deliver services and provide coaching on skills to help cope with mental health issues.

### ***Education and awareness:***

- Several respondents suggested that more education on mental health issues particularly in faith centres. They felt that discussion of mental health in faith centres would help 'reduce stigma and encourage people to use community support'.
- Some respondents mentioned that more awareness in the community, using local media would have helped them.

### ***Counselling and other related services:***

- Counselling services available quickly, gender specific and in their own languages were suggested by several respondents, home visits were also mentioned.
- When asked if there was anything else that would have helped respondents, there was strong support for counselling services available immediately on leaving hospital and home visits.
- Counselling available for women and families specifically was mentioned, using BME counsellors.
- One respondent felt it was important that BME specialist maintain professional standards in services.
- Importance of G.Ps was mentioned as a key point of contact who should be aware of local voluntary services and provide a link to services.
- Direct access to services was also requested, with focus on the delays it takes to receive treatment, resulting in respondents having to pay for private services.



## **Section 7.8 Appendix 8: Treatment and Medication Brief**

### **Medication:**

- 3 respondents stated that they requested a change in medication due to unpleasant side effects.
- 7 respondents stated that the GP/Psychiatrist explained clearly the side effects and dosage of medication.
- 2 respondents said they were given no information or that they didn't remember being given any.
- 3 respondents stated that they were only partly informed about their medication.

### **Follow up support:** After leaving the hospital:

- 2 respondents indicated that they received support through Social Worker visits, and a trainee social worker
- 1 respondent indicated that they received support through a support worker.
- 1 respondent indicated that they received support through a CPN.
- 1 respondent indicated that their family and their therapist were their main source of support.

Did you understand the information provided about you medication?

<b>Response</b>	<b>Number</b>
No	10
Yes	9
No response	2
N/A	2
<b>Total</b>	<b>23</b>

Were you ever hospitalised? If yes, were you:

Isolated	1
Segregated	0
Discriminated against due to race or colour of skin	1
Other, please specify	4
N/A or No response	17
<b>Total</b>	<b>23</b>

How involved were **you** in the planning/design of your care plan?

Very involved	0
Somewhat involved	2
Neutral	2
Rarely involved	0
Not at all involved	9
No response or N/A	10
<b>Total</b>	<b>23</b>

How involved was your **carer** in the planning/design of your care plan:

Very involved	1
Somewhat involved	3
Neutral	4
Rarely involved	0
Not at all involved	3
No response or N/A	12
<b>Total</b>	<b>23</b>

## **Section 7.9 Appendix 9: Case Study**

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Respondent is a 26 year old Sikh female who has had mental health issues from an early age and is also a carer for her mother who has chronic physical and mental illness.

### **This is her story as a Service User in her own words.**

Her first contact with services when she was very young:

*"I was stressed out, I saw the GP because I was wetting the bed and for some reason the doctor thought that my mum was hitting me and that's why I was wetting the bed. Then I was locked in a room with a woman (social worker), and I could hear my mum outside literally screaming to get me out. They were trying to get me away from my mum. I was asked all sorts of questions because they thought she was hitting me. It was very stressful".*

### **Later in her teenage years:**

*"I felt suicidal, alone, like I couldn't go on anymore. I knew ... that this wasn't right and thought I had to see a doctor. I tried talking to family first but got no help there. I was at school at the time and found it difficult to cope with things. Because I was really young, I just closed up at first – I couldn't talk to anyone about it. Then I went to my GP because a friend had passed away and I couldn't handle that. I was about 15/16 at the time...I was asked if it would help if I had someone who was Asian, I said yes. Between the time I asked and seeing the psychologist it was only a matter of weeks. Because I was a kid I think they had to deal with it straightaway..*

*The GPs were unhelpful, I was very dissatisfied. To be honest, it took me a few times before I could get to see somebody. They just wanted to give me anti-depressants - I was 14 when the doctor started talking to me about Prozac. At such a young age, I knew that wasn't right. I got knocked back about 3 or 4 times before I talked with a GP for about 25 minutes...They just want to prescribe you meds, that's always the issue, I just don't go now, I've found different coping mechanisms now. I had to literally force them into letting me see somebody. I knew I needed to speak to somebody.*

*Its not as if I hadn't tried to talk to people around me and get support. My friends didn't understand. I tried to talk to my family and was knocked back and I still am. From my community I was ignored. Nobody bothered at all. And that's when I turned to my doctor, when I had given it a good couple of years trying to sort it myself.*

*If I hadn't got the smarts I had I probably would've turned to something like drugs or dependency or attention seeking or been an alcoholic, or smoking, or I would've had habitual kind of tendencies but I haven't. I kept true to my religion and my faith and I've got through a lot.*

*I saw a child psychologist for about 4 years. I felt more confused I didn't feel like I got any help...because if anything, it raised more issues for me than it solved...I had an Asian child psychologist. You can have Asians in lots of roles where they could really help our community out but they just don't have the right attitude about it...they are not professional, and they will take the easy route and cut corners. There's a lot of 'don't worry, we'll sort it' and then they don't follow procedures properly or show enough caring. There's very few Asian people who you'll get being professional.*

*You're spinning and you want someone to pull you out of it. Seeing a counsellor doesn't give you tools to get out of that spinning. They would ask you questions near the end of the session and finish the session in an hour and leave you open. I used to cry afterwards and it made me feel worse. I*

would never go to my doctors for depression again.

*You're told that if you ever have a problem you should go to the doctors, or there lots of places like Relate, you get leaflets at school and college and I did go because I trusted these things would help me. I was told I had those places to go but when I went there why did they not help? Why were they treating me just as a job, 'here's your hour'. Its unfortunate that I got slapped in the face by so many avenues. I had to force myself out of depression and I used my faith. I was young (17/18) when I realised nobody cares apart from me, that I'm going to be the only person who will help myself.*

*I would never use the services again; I would never go to the doctors for this again, no never".*

### **Regarding support:**

*"I didn't have any support from the immediate people that you'd assume to have support from such as community and family. There was no support for depression, for upset, for my emotional state. That's why I was at the point where I was bursting and I had to talk to somebody.*

*Sometimes you don't need 'somebody' to give the support. I go to the Gurdwara everyday but sometimes I go extra. I just need to be with my own thoughts, I feel safe there, its peaceful. I feel safe from all the negativity.*

*I also use self-help books, I read books because there's no alternative".*

### **Recommendations as a service user**

*"GP's should have access to information about comments that people have made, like this research, about cultural awareness. They should be trained using case studies, and people who have been through it, been through the bad experience, there should be more service users involved in training for doctors.*

*There should be more coaching on life skills, giving you tools to deal with life issues and it should be something that's very obvious – easy to see and find. It should be run by trained professionals (not people who are just going to the 'next project') and they should be of mixed ethnicity. They shouldn't use an Asian name, it should be something that is relevant in all cultures – almost like a shoulder!*

*Also there needs to be a telephone helpline, something like the Samaritans but with an option to book in to see them also afterwards. This can be run by the NHS or a private organization (private tends to have better standards). There should be standards, it should be clear what they're there for – not just filling in job applications and other forms. There should be a precise and concise service to meet mental health needs only.*

*There should be respect for individuals, treating everyone as individuals. A professional service – not a conveyor belt one in one out. Counsellors have about 15 minutes between appointments which is not enough to switch off and restart. Many times I could tell my counsellor had not recovered from the last session.*

*The biggest thing I'd say is treating people as individuals. Somebody may come from the same background and have the same upbringing but they've got their own personality, their own individuality and they'll have their own issues.*

*Cultural awareness training. Not making assumptions based on your ethnic origin. May be they need to be culturally aware. Sometimes Asian doctors don't have cultural awareness, they may have*

*had a more mainstream upbringing or they may not have cultural knowledge.*

*I don't think GPs have heart and compassion, they have medical knowledge but they don't have emotional/psychological training to deal with patients with mental health issues. The GPs are the biggest problem, they stereotype you, put you into little boxes and make assumptions about you".*

### **What improvements do you want to see?**

- *Professionalism*
- *Compassion and human respect*
- *Treating you as a person not as a statistic*
- *No stereotypes or assumptions of Asians*
- *Asians working in the services should have more knowledge of all aspects of Asian culture and should realise their impact on patients".*

### **How do you feel now?**

*"Stronger. But I feel disappointed that I had to go through so much to get to this point - it took me 10 years".*

### **Her story as a carer:**

This participant became a carer at a young age by seeing that services were not helping her disabled mother. Some counselling sessions her mum had at home resulted in her becoming upset and her mental health problems increased. Her mother had also been painted a gloomy picture by doctors of her life expectancy and chances because of her physical condition - she overcame most of these obstacles with her own determination.

*"I have spoken to my mums GP about her being depressed and...said they're not helping the situation because they call her a hypochondriac and she's not. They don't understand the part the medical services have played in her emotional health. You're bound to be upset and depressed when you're being told that you're going to drop dead in 3 months, that you cannot have kids, being told that you'd better do the last things you want to do because you haven't got long to live. They played a big part and I was reminding them of that part and that she needs help and if you're not going to help at least treat her with respect.*

*I get a regular carer's newsletter coming through the post saying 'come round for tea'. I can drink tea at home, give me someone to help me with the shopping and cleaning and I'll be there like a shot. Maybe I have a stereotype view but I see these things as not a form of help but as a form of escapism. I don't see her disability and MH issues as a problem to be escaped from but as something to be dealt with and something I need help to deal with".*

### **Recommendations:**

There should be support or aftercare after each counselling session. There needs to be more home visits - services delivered in the home. It would be good to see disabled people giving advice, support and counselling. Asian counsellors should have an awareness of all aspects of their culture and have professional standards.

There should be more advice about coping mechanisms. Perhaps a 24hr helpline providing advice and coping mechanisms, and they should be able to book an appointment for them to see you also if needed. This can be volunteer or NHS, but needs to have professional standards.

Support group -but not only with other carers also with people outside the area-sometimes you want

to speak to someone who isn't immersed in the problem.

