



ROOTS-TO-ROUTES

REPORT

of

THE COMMUNITY LED RESEARCH PROJECT FOCUSSED ON THE EXPERIENCE OF PEOPLE FROM BLACK, ASIAN AND MINORITY ETHNIC GROUPS IN ADULT ACUTE MENTAL HEALTH SETTINGS IN REDBRIDGE

A qualitative research study aimed at improving the quality of mental health care for a culturally diverse community.

BY

RUN-UP

(Redbridge User Network User Pressure Group)

March 2007



National Institute for
Mental Health in England



SAY IT LIKE IT IS

"I think a mental health hospital must be the closest place to hell on earth"

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"I can't really explain why, I just think, just felt sometimes like I was just being punished"

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"Boredom is the main thing, the main problem, a struggle".

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"I didn't like it because there's nothing to do especially in Goodmayes"

"I didn't like it because there's nothing to do especially in Goodmayes"

"But I'm not sure he valued my opinion"

"But I'm not sure he valued my opinion"

Who's who?

(Members of the research project team)

Nikki

I got involved in this project relatively late (January 07) but what first stuck me was the huge amount of effort by all the team to actually get this research project passed through all the legalities and ethics.

As an ex-service user who lives in Redbridge and a counsellor by profession, this project provided me with an opportunity to learn more about how the service users these days and in particular what service users from ethnic minority groups feel about the services they receive from Redbridge.

Yes, at times it was challenging, in the sense of the effort it took to co-ordinate ourselves as the research team but the motivation, dedication and sensitivity in the way the interviews were carried out, meant that I for one felt honoured to be part of this research.

Steve

Being involved with the project has opened my eyes to the problems that individuals with mental health problems encountered when in hospital and even after they are discharged back into the community.

Harkirat

Harkirat was employed on this project as a Community Researcher. Harkirat has recently completed a BSc degree in Psychology at the University of Bristol, and has been involved with many voluntary organisations in the past.

From this research she hopes to have consolidated her research skills and have gained insights into diversity issues and the mental health system in Redbridge.

Terrence

Commissioned as the chief researcher on the project; a senior mental health manager and community worker with over 20 years experience

Being involved in this project provided an opportunity to learn more about how service users from minority groups feel about the service they receive. It also presented a challenge to redouble one's efforts and join forces with others to promote equality of treatment for all across the mental health user group in Redbridge.

Christine

Christine is the founder and manager of Run-up. She is passionate about and dedicated to the improving of mental health services for all service users.

Christine has led the research project team with equal care and professionalism and her hope is that this report contributes positively to the improvement of mental health services across Redbridge.

Marilyn

Although Marilyn joined the project team later than many, that was no hindrance to her enthusiasm and effort that she put into conducting the discovery interviews and her invaluable contribution to planning the project.

Other team members

Terry: The project's first administrator and a dedicated team member. Unfortunately, due to personal circumstances, Terry was unable to see the project to the end.

Sameer, Catherine, Jan and Caroline are other members of the research team who have contributed significantly to the project, but who, through personal circumstances were unable to continue for the duration of the project.

ACKNOWLEDGEMENTS

We gratefully acknowledge the National Institute for Mental Health in England (NIMHE) which provided the funding for the project; also The University of Central Lancashire (UCLan) for the comprehensive training and support provided throughout the duration of the project. Special thanks to the project team who volunteered their time and effort to plan, organise and deliver this project efficiently; also the steering committee which provided guidance, support and resources to the project team. Thanks to North East London Mental Health Trust (NELMHT), Redbridge Primary Care Trust (PCT), Psychology Department, Home Treatment Team, Goodmayes Hospital ward Managers and staff, Community service providers and Redbridge Concern for Mental Health for their kind support to the project. Thanks also to the NHS and R&D ethics governance committee for granting us approval to carry out this important study.

Special thanks to the five service user participants without whom this report would not be possible. To Imran, the project academic support worker, for his patience and professional contribution to the project.

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Executive summary

This report presents the findings of a pilot study conducted by Redbridge User Network User Pressure Group (RUN-UP) among mental health service users in the London borough of Redbridge area of North East London Mental Health Trust (NELMHT). It describes the experiences of service users from Black, Asian and Minority Ethnic groups in the borough. It does not make specific recommendations on mental health policy, which falls outside the scope of this study. It does, however highlight specific areas for improvements that participants have indicated would benefit them.

Research Focus

The study involved five (5) service user participants from different backgrounds. Participants were encouraged to talk about their experiences at each stage of their journey through mental health assessment, admission and discharge. Throughout the interview process particular reference was made to the cultural relevance, appropriateness and effectiveness of the care received by the user.

Research Consultants

A team of trained consultants, many of whom have also experienced mental health problems and can identify with those of the participants, conducted the research. Other consultants include a carer, and befriender of mental health service users.

Research Methodology

The discovery interview method was used during the study. It includes a spine of questions as a guide for the interviewer. Discovery interviews are essentially semi-structured interviews, using the spinal questions to help individuals to tell the story of their own journey through an episode of health and/or social care.

The spine of questions includes the following:

- Realising something was wrong
- Making contact with health and social care agencies to ask for help
- Involvement in decision-making and care planning
- Experience of the service and staff
- Support at discharge stages

Research Sample

Participants in the study include four (4) men, one each from Black African, Asian Indian, Asian Pakistani and Jewish background. There was also one (1) female from Asian Indian background. All participants were British; two were born in the UK and three had lived in the UK for 11 or more years. The ages of participants range from 18 to 49 years.

The Home Treatment team was very supportive in helping to identify suitable service users for the study. Much effort was put into liaising and working with the wards to identify patients who would participate in the study. Despite the effort to work with the wards on this project, the response was poor in regard to the referral of suitable candidates for the study; in the end none of the participants was referred from the wards.

However, all five participants in the study have had in-patient experience at one or more of the hospitals in the NELMHT region.

Basis of the study

The current national modernisation agenda for both the NHS and Social Care Services emphasises the need for the individual to be at the centre of the care they receive from statutory services. Furthermore, improving the quality of care for people within inpatient settings is a key standard within the National Service Framework for Mental Health (1999), and within the Delivering Race Equality (DRE) (2003) initiative for mental health services.

The key conclusions from the stories of the five participants, along with further details of the consultation process are set out in this report, taking into account the DRE vision for mental health.

Challenges

A significant challenge faced by the research team concerned obtaining ethical approval for the proposed research. The role of the various ethics committee is to ensure the wellbeing of participating patients and service user and to ensure that the study conform to established standards of research.

There are lessons to be learned from this experience which are important to share with both statutory and voluntary sector groups who may be embarking on similar projects. In summary, we would note the following:

- Difficulties in navigating a pathway through the range of bodies and processes involved e.g. Research & Development Departments , NHS ethical governance, on-line forms to complete – a local guide or information on ‘who and how’ would be extremely helpful
- The unanticipated amount of time required to complete the paperwork required, make contact with the right people, etc
- The impact this had on the morale and confidence of the team.
It was particularly frustrating when key individuals within the Trust who are connected to the ethical governance team failed to respond to our request for vital information. This experience put the project team under severe pressure and in a disadvantageous position, as the balance of power remained with the statutory service, which was not forthcoming with the necessary information or support in this regard. As a consequence of this experience some members of the research team were not able to continue and withdrew from the project.

The challenges faced by the remaining service user consultants on the project team were compounded by the fact that through conducting the interviews they came face to face with experiences that they themselves have had to deal with during their personal connection with the mental health services.

The possibility that the feelings in participants will be aroused was acknowledged and appropriate provision made to responded to these sensitively through the psychology department. However, none of the participants had the need for psychological support after the study.

In general, the problems experienced significantly impacted both on the members of the research team and the consultation process. As a consequence, the scope and timetable of the project have had to be modified. Throughout all of these processes and events, the research team valued the support and encouragement of the local project steering group and UCLAN.

Data analysis

In this report, the results are standardised for age and gender, including those relating to admission, detention, care programme approach and involvement. The report uses the accepted method of taking account of age and gender differences between groups to show the ratios of participations.

Data was collected by way of electronic tape recording and transcribed by members of the research team. The process of recording and transcribing was very labour intensive and which puts a lot of strain on the research team.

Conclusion

Having regard to the report findings and the recorded experiences of the participants in this research, it is clear that over the years mental health services have improved in some areas, much to the delight of some service users. However, the participants have identified areas which require fundamental changes if service users are to have confidence in the service. One critical area for improvement identified by service users is the provision of relevant information to patients at the right time during their contact with the service.

The list below indicates what one service user would like from the service:

- ❖ *I would like to have been explained, the procedures and what would happen like;*
- ❖ *who I was with*
- ❖ *where I was going to be*
- ❖ *how long I was going to be there for*
- ❖ *could I contact my relatives*
- ❖ *could they come in and see me*
- ❖ *to be freer, like they would treat you as a medical patient*
- ❖ *more information on the range of community support services before discharge*

In addition, service users would like changes in some common practices, to be consulted and to be more involved in certain areas of the delivery of care and support. Areas that participants would like to address include:

- ❖ Clear explanation from staff regarding the procedures surrounding the access and discharge processes. In particular, patients need to know the difference in procedures that apply to voluntary in patients and those who are statutorily detained
- ❖ The structure of ward meetings to be more user-friendly (less frightening)
- ❖ Staff to attend to the physical as well as mental health and social needs of patients
- ❖ Consideration to be given to participants holistic needs; including family, pet care, household bills etc.
- ❖ Staff to ensure service users have relevant information about care procedures, (e.g. information on diagnoses, and treatment)
- ❖ Provision of suitable activities on one ward should be the same on all wards
- ❖ Patients to be more widely consulted about activities on the wards or organised by trust staff
- ❖ Patients would like to have a wider variety of activities
- ❖ Less movement of patients between hospitals, wards and locality
- ❖ Where movements are necessary participants would like to have clear communication and information about it.

Finally, the good work of the Trust must be recognised to gain and retain the confidence of patients in the care and support processes. One participant clearly states:

“As I’ve seen it since August it’s a definite change, even inside the system, not just the system where once you leave hospital. There’s a definite improvement within the system once you’re in hospital. It’s very different; it’s well structured and hopefully it will stay this way. I hope it doesn’t go back to the old way because you know it was not very good for us patients”

Recommendations

There are a number of steps that can be taken to help reduce the problems, indicated by the service user participants in this report. For example:

1. Ward (consultation) meetings

- Ward managers should ensure that the experience of patients at the point of admission is more pleasant and welcoming. For example, involve relatives, advocates, interpreters and support workers in the process.
- Ward meetings should be more user-friendly. This can be done simply by rearranging the layout of the room in a less formal way and perhaps providing refreshments etc for patients.

2. Holistic patient care and support

- Ward managers and staff should seek to attend to the physical, social needs as well as the mental health of patients. For example, one participant complained that nursing staff refused to attend to his cry for pain in his legs.
- Consideration should also be given to the patient's day to day issues such as health & safety at the patient's home, e.g. is their home secured for the duration of their admission, care for house pets, payment of household bills etc.

3. Information to patients (DRE better information)

- Hospital admission policy and procedures (e.g. information on diagnoses, treatment options, duration of admission etc) to be explained to patients.
- Commissioners and Providers should provide information to patients of culturally appropriate community services before discharge.
- Providers should work collaboratively and in a capacity building way with community and voluntary service providers to increase and improve the service to patients.
- Commissioners should take steps to increase public knowledge on where to get help during a mental health crisis.
- Staff to provide clear explanation to patients about the procedures surrounding the access and discharge processes.
- In particular, managers and staff should ensure that patients know the different procedures that apply to voluntary in-patients and those who are statutorily detained.

4. Social Activities

- Managers should consult service users more widely about activities on the wards or organised by trust staff.
- Ensure that activities provided on one ward are common to all the wards.
- Provide a wider range of activities on the wards
- Staff should maximise the vast resources within the voluntary sector e.g. day centres and Capital Volunteering Program

5. Less movement of patients between hospitals, various wards and locality

- To limit the movement of service users/patients between wards, hospitals and locality.
- Where it is necessary to relocate a patient, this should be clearly communicated and relevant information provided to the patient regarding the move.

6. Care & Cultural Background

- Staff should be trained in how to provide culturally sensitive care.
- Staff should record the languages of BME patients as part of the data collected from patients during the admissions process.

7. Culturally Appropriate and Responsive Service

- All BME patients should be offered alternative treatment such as Home Treatment and OT services; from the interviews conducted only one participant was offered alternative service.
- All BME patients should be offered culturally appropriate talking therapies such as counselling and psychological support as alternative treatment.
- Staff to inform patients of the alternative treatments available as soon as possible to enable informed choice

1. Introduction

This document sets out clearly the views and experience of service users within the North East London Mental Health Trust (NELMHT).

It is the culmination of a pilot study, which involved a three month process including training, research, planning and consultation with service user participants.

The research was conducted and managed by the service user group Run-Up, and included consultants who are also service users, carers and friends of the mental health user group in Redbridge.

The sample size of this study was seriously affected by the delay and difficulties encountered throughout the process; particularly, surrounding the ethical governance approval.

Although the sample size is smaller than first planned, the research team strongly believe that the experience of the five participants in this research provide valuable and undeniable information that commissioners and providers should be attentive to and use constructively to improve the service generally.

2. Aims and objectives

The main aims of the study is to contribute to improved quality of care and support for individuals from Black, Asian and Minority Ethnic (BAME) groups in acute inpatient mental health care in Redbridge.

To understand what individual service users/patients from BAME groups perceive as important in the process of care assessment, planning and service delivery within the adult in-patient mental health setting.

To enable service users/patients to directly influence how inpatient treatment and care are developed across Redbridge.

3. Principles of the Study

Outlined below are the principles that underpin the study:

- 3.1 Previously conducted research have shown that there are major differences in the way that Black African and Caribbean people come into contact with mental health services and in the benefit they derive from them, compared with the rest of the population. (Delivering Race Equality in Mental Health Care (DRE), Department of Health, 2005a).

The Government report "Inside Outside" (2003) reported; "There does not appear to be a single area of mental health care in this country in which black and minority ethnic groups fare as well as, or better than, the majority white community. Both in terms of service experience and the outcome of service interventions, they fare much worse than people from the ethnic majority."

Other publications that address the issues include:

- Department of Health's Modernisation Agency Publication (11 May 2005)
- Mental Health Policy Implementation Guide (Community Development Workers for Black and Minority Ethnic Communities Final Handbook - November 2006.)
- The National Service Framework (1999)

- The Costs of Race Inequality – Policy 6 (Sainsbury Centre - October 2005)
- 3.2 The need to address disparities in access, experience and outcomes is widely recognised and Run-Up is one of the groups that is trying to address these issues in the local community.
- 3.3 This document is about adult mental health services in Redbridge. It represents the experiences of people with a wide range of mental health problems from different backgrounds and is a culmination of what we have learned by talking directly to people who have at some stage during their mental illness, received hospital treatment from NELMHT.
- 3.4 The study was conducted and the report prepared by a project team including, consultant researchers, some of whom are service users, carer and befriender. Researchers have received formal training through the University of Central Lancashire (Uclan) in how to conduct community research. Further support was provided to the project team by support workers from Uclan and a local multi-disciplinary steering group. (See para 5)
- 3.5 The current national modernisation agenda for both NHS and Social Care Services emphasises the need for the individual to be at the centre of the care they receive from statutory services. Improving the quality of care for people within inpatient settings is a key standard within the National Service Framework for Mental Health (1999), and within the Delivering Race Equality (DRE) (2003) initiative for mental health services. In 2005, the North East London sector became a focused implementation site for the national DRE programme (Department of health Jan 05).
- 3.6 The government continue to emphasise the need to place the person at the heart of a modernised health and social care system, embracing cultural diversity within the range of service delivery processes. In the recent Health and Social Care White Paper; “Your Health, Your Care, Your Say” (DH 2006), this theme is continued in respect of integrated assessment, care planning and service delivery.
- 3.7 North East London Mental Health Trust offers a range of community based mental health services for people with serious and enduring mental illnesses. At the heart of these services are community mental health teams. Currently, there are two community mental health teams in Redbridge. In addition, there is a number of community based services provided by the voluntary sector.
- 3.8 The National Service Framework for Mental Health has introduced further ways of providing services which are more responsive to service users and designed to keep people out of hospital as far as possible. In Redbridge, the established ‘Home Treatment Team’ offers an alternative to inpatient care by providing home assessment and support to those suffering from functional mental health conditions.
- 3.9 According to a report published by the Director of Public Health at Redbridge Primary Care Trust in 2004, it is estimated that the number of people living in Redbridge with various types of mental health problem are as follows:
- 26,000 people with anxiety or depression
 - 6,000 people with other common mental health problems, such as phobias or panic attacks,
 - 6,000 people with personality disorders,
 - 3,000 people with dementia, and
 - 1,000 people with psychotic illnesses such as schizophrenia or manic depression.

The Redbridge PCT, Public Health Report, (2004-2005) on page 21 below, indicates that a significant 36% of these people are from BME background.

- 3.10.1 This research seeks to strengthen and support the case for action set out in the DRE (2003) vision by adding the users views to the hypothesis for better mental health services for Black and minority service users. This pilot study acknowledges however, that further research on the effectiveness of mental health care for Black and minority people is needed to validate this hypothesis.

4. Research Methodology

The method of consultation used during this pilot study was 'Discovery Interviews'.

Discovery Interviews are essentially semi-structured interviews, which ask the individual to tell the story of their personal journey through an episode of health and or social care. There are no formal direct questions as the aim is to enable the individual to tell their own story of their experience in their own words.

This interview methodology contributes significantly to the rationale for using the technique, which is to ensure the development and implementation of appropriate person-centred and culturally sensitive inpatient mental health services; led by users rather than solely by professionals.

The discovery interview method was developed initially through the Coronary Heart Disease (CHD) Collaborative, part of the Service Improvement Directorate of the Department of Health's Modernisation Agency (11 May 2005).

To support the researchers during the consultation process, a framework or 'spine' was developed as guide to the interviewer. The spine is a set of prompts for the interviewer to ensure that the interviewee is guided through the various stages of their journey in relation to the particular aspect of service.

The spine is the basic framework, which underlies all Discovery Interviews.

The content of the spine used in this study is based on mapping of the existing assessment and care planning processes for mental health users of acute mental health hospital care. The key stages of the spine relate directly to the key stages of an individual's journey through the system of care and include the following:

- First realising something was wrong
- Making contact with health and social care agencies to ask for help
- Being assessed
- Involvement in decision-making and care planning
- Experience of services
- Monitoring and reviewing needs and services
- Outcomes of the care episode
- Support at discharge

Participants are encouraged to talk about their experiences at each stage.

5. Study Design

The study was agreed by the Redbridge Partnership and Planning Group for Mental Health and the mental health Local Implementation Team (LIT). This Group was set up to oversee the implementation of the National Service Framework (NSF) and

sound mental health policy within Redbridge. Membership of the group includes representatives from relevant partner agencies such as:

- London Borough of Redbridge Community Services (Social Care and Housing services)
- Redbridge Primary Care NHS Trust
- North East London Mental Health NHS Trust
- Redbridge Concern for Mental Health
- Redbridge Carers Support Service
- Redbridge User group
- Capital Volunteering Redbridge
- NHS Direct

The LIT agreed the design of the study and provided guidance to the project team through the monthly multi disciplinary steering group meeting. Redbridge Concern for Mental Health and the user group RUN UP were commissioned to carry out the study on behalf of the LIT. Expertise on Discovery Interviews was provided by Redbridge Primary Care Trust and academic support by the University of Central Lancashire (UCLAN); The project was funded by National Institute for Mental Health in England (NIMHE). Ethical governance was provided by the NHS Ethics Committee and Redbridge Research and Development Department (R&D); The R&D also peer reviewed the project.

6. Approach & time-scale to the study

This research was undertaken over a three month period, January to March 07. The study was managed by a project team with membership from service users, carer and befriender.

7. Data analysis

In this report, the results are standardised so that no distinction is made in regard to age and gender, in those data relating to admission, detention, care programme approach and involvement. The report, however, uses the accepted method of taking a general account of age and gender differences to show the ratios between the participants.

Data was collected by way of electronic tape recording and transcribed by members of the research team. The process of recording and transcribing was very labour intensive and which puts a lot of strain on the research team.

8. Challenges

A significant challenge faced by the research team concerned obtaining ethical approval for the proposed research. The role of the various ethics committee is to ensure the wellbeing of participating patients and service user and to ensure that the study conform to established standards of research.

There are lessons to be learned from this experience which are important to share with both statutory and voluntary sector groups who may be embarking on similar projects. In summary, we would note the following:

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ethical governance, on-line forms to complete – a local guide or information on 'who and how' would be extremely helpful

- The unanticipated amount of time required to complete the paperwork required, make contact with the right people, etc
- The impact this had on the morale and confidence of the team.
It was particularly frustrating when key individuals within the Trust who are connected to the ethical governance team failed to respond to our request for vital information. This experience put the project team under severe pressure and in a disadvantageous position, as the balance of power remained with the statutory service, which was not forthcoming with the necessary information or support in this regard. As a consequence of this experience some members of the research team were not able to continue and withdrew from the project.

The challenges faced by the remaining service user consultants on the project team were compounded by the fact that through conducting the interviews they came face to face with experiences that they themselves have had to deal with during their personal connection with the mental health services.

The possibility that the feelings in participants will be aroused was acknowledged and appropriate provision made to responded to these sensitively through the psychology department. However, none of the participants had the need for psychological support after the study.

In general, the problems experienced significantly impacted both on the members of the research team and the consultation process. As a consequence, the scope and timetable of the project have had to be modified. Throughout all of these processes and events, the research team valued the support and encouragement of the local project steering group and UCLAN.

9. The focus

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

The mental health user group, RUN-UP, in Redbridge is a community group which took part in the Community Engagement Programme sponsored by the National Institute for Mental Health in England (NIHME) in 2006/7.

The focus of this pilot study is to record the views of service users from Black, Asian and Minority Ethnic groups (BAME) of their experience of the care received from adult acute mental health inpatient settings in Redbridge.

The aims of the study include:

- To understand what individual service user/patient from BAME groups perceive as important in the process of assessment, care planning and service delivery within the adult inpatient mental health setting.
- To enable service users/patients to directly influence how inpatient treatment and care for adults from BAME groups is developed in Redbridge.
- To agree and contribute to the agenda of ways to deliver improved mental health inpatient care.

- To contribute to the delivery of improved quality of acute inpatient mental health care assessment, care planning and service delivery for individuals from Black, Asian and Minority Ethnic (BAME) groups in Redbridge.

The study includes the stories of 5 service user participants, using 'Discovery Interview' methods. Participants were identified through partnership working with User groups, Statutory and Voluntary sector service providers such as the Home Treatment Team, Ward Managers, Mansfield Road and Ley Street resource centres.

10. Background to the Community Engagement Model

We often hear the following words or phrases:

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

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

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

If all the DH had wanted was a needs assessment and a 'glossy report', they could have commissioned researchers and produced yet another set of reports that may have had little long term impact. However this scheme was to be different. The DH was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about drugs, or anything about undertaking a needs assessment at the start of the project; however they would have proven access to the communities they were working with, the potential to be supported and trained, and the infrastructure to conduct such a piece of work. They would be able to use the nine-month process to learn about drug-related issues, and how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity and Health Unit would provide, and they would learn from actually managing and undertaking the work. In this way, at the end of the process, there would be a number of individuals left behind in the community who would have gained from undertaking this work. They would have learned about drugs, and learned about the needs of their communities, and they would be able to continue to articulate those needs to their local service providers, and their local Drug Action Teams (DATs). It

was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

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

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

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

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

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

11. The key ingredients of the model

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

The key thing is that this host community organisation should have good links to the defined target community¹, such that it is able to recruit a number of people from the target community to take part in the project and to do the work (see section on task below).

It is important that the host community organisation is able to co-ordinate the work, and provide an infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day-to-day activities of the project. One of the

¹ The target community may be defined in a number of ways – in many of the community engagement projects it has been defined by ethnicity. We have also worked with projects where it has been defined by some other criteria, such as age (e.g. young people); gender (e.g. women); sexuality (e.g. gay men); service users (e.g. users of drug services or mental health service users); geography (e.g. within a particular ward or estate) or by some other label that people can identify with (e.g. victims of domestic violence, sex workers).

² This is not always possible, for example, where potential participants are in receipt of state benefits and where to receive payment would leave the participant worse off.

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

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

The final ingredient, according to the Centre for Ethnicity and Health's model, is the provision of appropriate support and guidance. It is not expected that community groups offer their time and input for free. Typically a payment in the region of £15-20,000 will be made available to the host organisation. It is expected that the bulk of this money will be used to pay people from the target community as community researchers². A named member of staff from the community engagement team is allocated as a project support worker. This person will visit the project for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers throughout the project. The University also provides a package of training, typically in the form of a series of accredited workshops.

The accredited workshops give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to form an appropriate steering group to support the project³.

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

12. The Community Engagement Team

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

³. Very often we will have helped groups to do this very early on in the process at the point at which they are applying to take part in the project.

Table 1. National Programme Directors

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

13. Programme outcomes

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

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

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

- a third of community organisations in the first tranche reported that new services had been developed as a result of the Community Engagement Programme.
- the vast majority of participants and stakeholders expressed high levels of satisfaction with the project.

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

14. About Redbridge

The 2001 census identified that there were 238,635 people living in the London Borough of Redbridge. This represented an increase in the population of about 3% since the 1991 census. The census confirmed a significant increase in the minority ethnic population from 21% in 1991 to 36% in 2001. In addition, the minority ethnic population is becoming increasingly diverse, although people of Asian origin form the largest minority ethnic group in Redbridge with 14% of local residents of Indian origin, 6% of Pakistani origin and 2% of Bangladeshi origin.

Table 2. Black and minority ethnic population of Redbridge 2001

Ethnic group	Percentage population – Redbridge	Percentage population – England
White	63.5	90.9
Mixed	2.5	1.3
Asian or Asian British	25.0	4.6
Black or black British	7.5	2.3
Chinese or other	1.5	0.9
Total	100	100

In terms of faith communities the 2001 census indicates that 6% of the population identified themselves as being part of the Jewish faith, 12% as Muslims, 8% as Hindus, 5% as Sikhs, 51% as Christians and 10% as having no religious affinity.

Over the past decade there has been an increasing and diverse population of refugees and asylum seekers in Redbridge. A report commissioned by the Redbridge Refugee Forum in 1996, which focused on the needs of refugees and asylum seekers, estimated that there were people from 49 different nationalities or ethnic groups in Redbridge. In 2000 the Redbridge Public Health report estimated numbers of between 7000 and 10,000 refugees or asylum seekers in the borough which amounted to a 100% increase since 1995.

Table 3. North East London Characteristics

Source: Redbridge PCT, Public Health Report, 2004-2005

Table 2.1 Socio-demographic characteristics by outer North East London PCTs						
Characteristics	Barking & Dagenham PCT	Havering PCT	Redbridge PCT	Waltham Forest PCT	London	England
Single People Living Alone*	10,487 (16%)	11,312 (12%)	14,469 (16%)	18,676 (21%)	664,802 (22%)	3,210,799 (16%)
Elderly Living Alone**	10,226 (15%)	14,306 (16%)	12,383 (13%)	11,051 (12%)	382,086 (13%)	2,939,465 (14%)
Lone Parents***	6,982 (10%)	5,160 (6%)	6,047 (7%)	8,518 (9%)	229,306 (8%)	1,311,974 (6%)
Couples****	31,681 (47%)	53,293 (58%)	46,885 (51%)	37,714 (42%)	1,266,088 (42%)	10,996,723 (54%)
Ethnic minority population*	15%	5%	36%	36%	29%	9%
Homeless Households living in temporary accommodation	879	604	2,139	1,670	63,593	n/a
Official ONS Unemployment Rates November 2003 (% persons)	3.3	1.7	2.6	4.1	3.5	2.4 (GB)
Crime Rate 2003/04						
Violence against the person	29.9	17.5	19.6	27.5	26.0	-
Sexual offences	1.4	0.8	1.0	1.2	1.4	-
Robbery	4.9	2.3	5.0	7.6	5.7	-
Burglary	13.7	9.6	12.5	15.0	14.7	-
Theft and Handling	43.5	37.9	47.7	52.7	62.6	-
Fraud or Forgery	10.6	7.5	12.0	12.9	10.9	-
Criminal Damage	24.8	20.4	17.7	20.6	20.6	-
Drugs Offences	4.8	2.1	2.3	2.8	4.5	-
Other Offences	1.5	0.7	1.3	1.2	1.6	-
TOTAL OFFENCES	135.1	98.8	119.2	141.6	147.9	-
Number of Asylum Seekers w/ending 5/03/04	2,050	291	886	1,157	34,020	n/a
Indices of Deprivation 2004 Average Score (Average Rank)	32.69 (26)	15.40 (211)	17.85 (174)	29.93 (44)	n/a	n/a
(Where Rank 1 is most deprived LA and 354 the least)						
Notes:						
* Source: Census 2001. Crown Copyright (Key Statistics, Household Composition, one person household: other, as a percentage of all households)						
** Source: Census 2001. Crown Copyright (Key Statistics, Household Composition, one person household: pensioner, as a percentage of all households)						
***Source: Census 2001. Crown Copyright (Key Statistics, Household Composition, one family: lone parent household, with dependent children, as a percentage of all households)						
****Source: Census 2001. Crown Copyright						
Homelessness Data, source: Greater London Authority, as at Jan 2004. Definition: Homeless households in temporary accommodation under the Housing Act 1996.						
Crime Data, source: Metropolitan Police. Note: Rates per 1000 population, Census 2001.						
Asylum Data, source: London Asylum Consortium.						
IMD 2004, source: Office of the Deputy Prime Minister.						

Map 1. North East London Health Trust

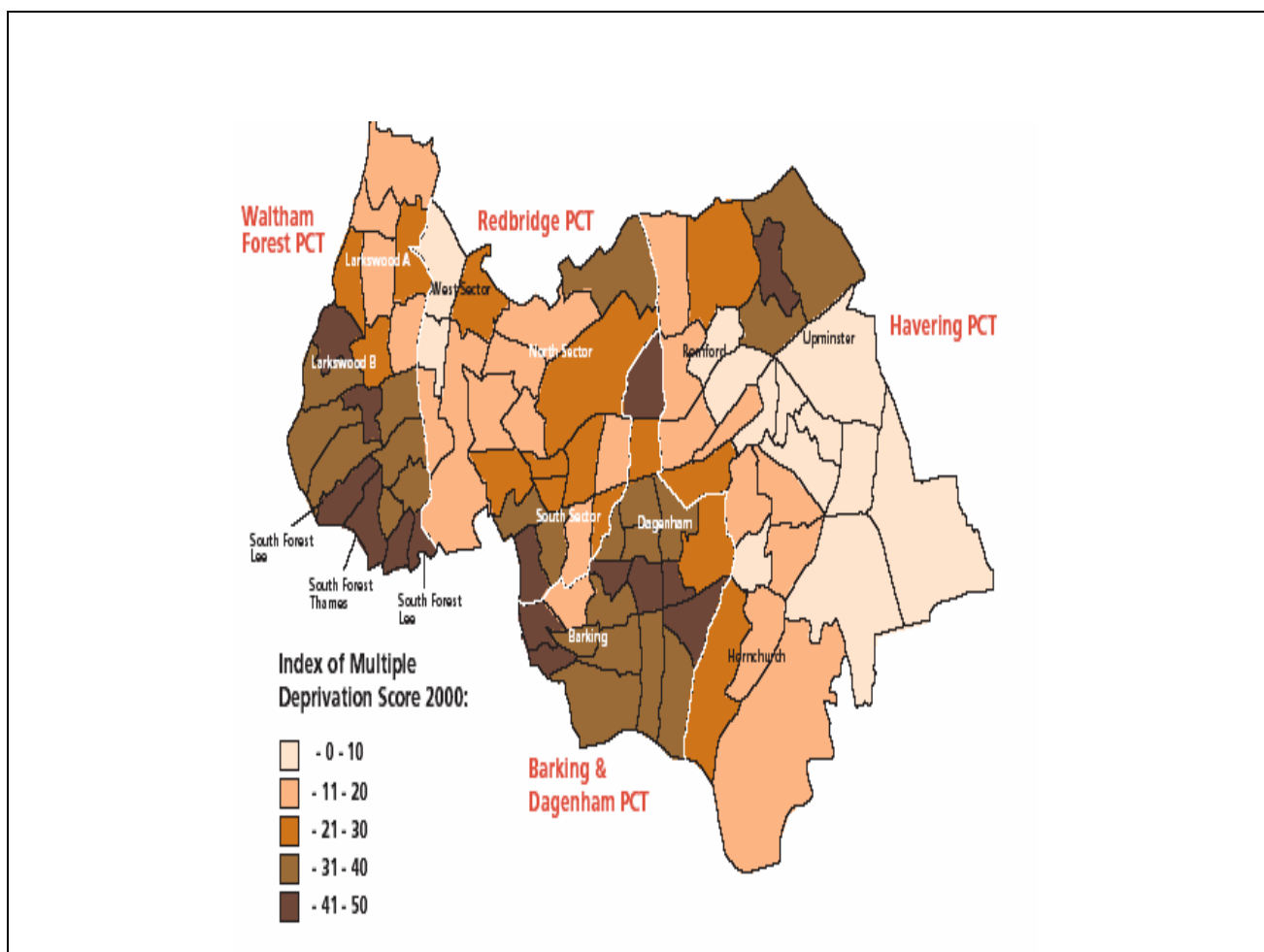
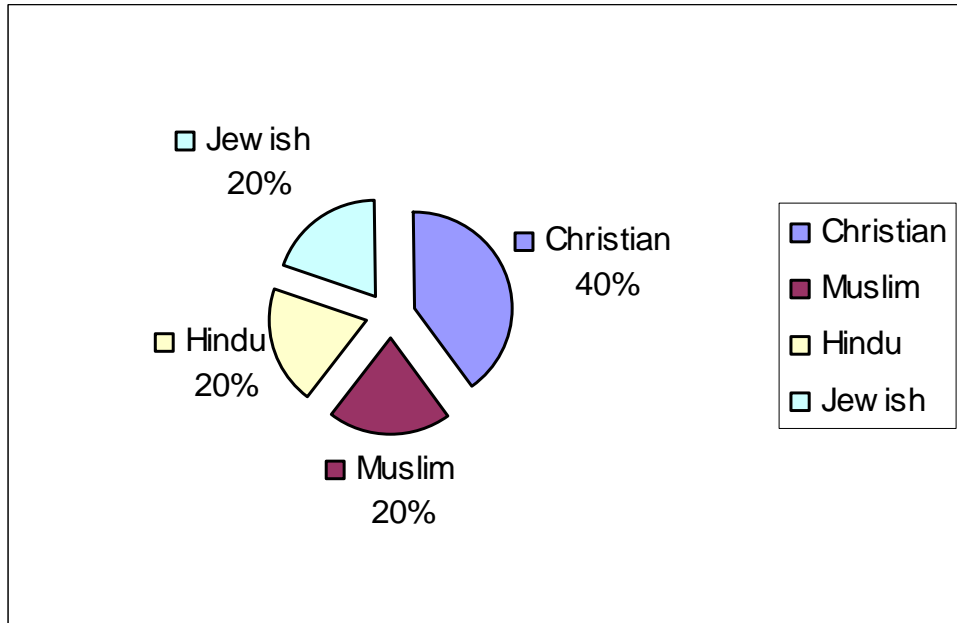


Table 4 CORE DATA

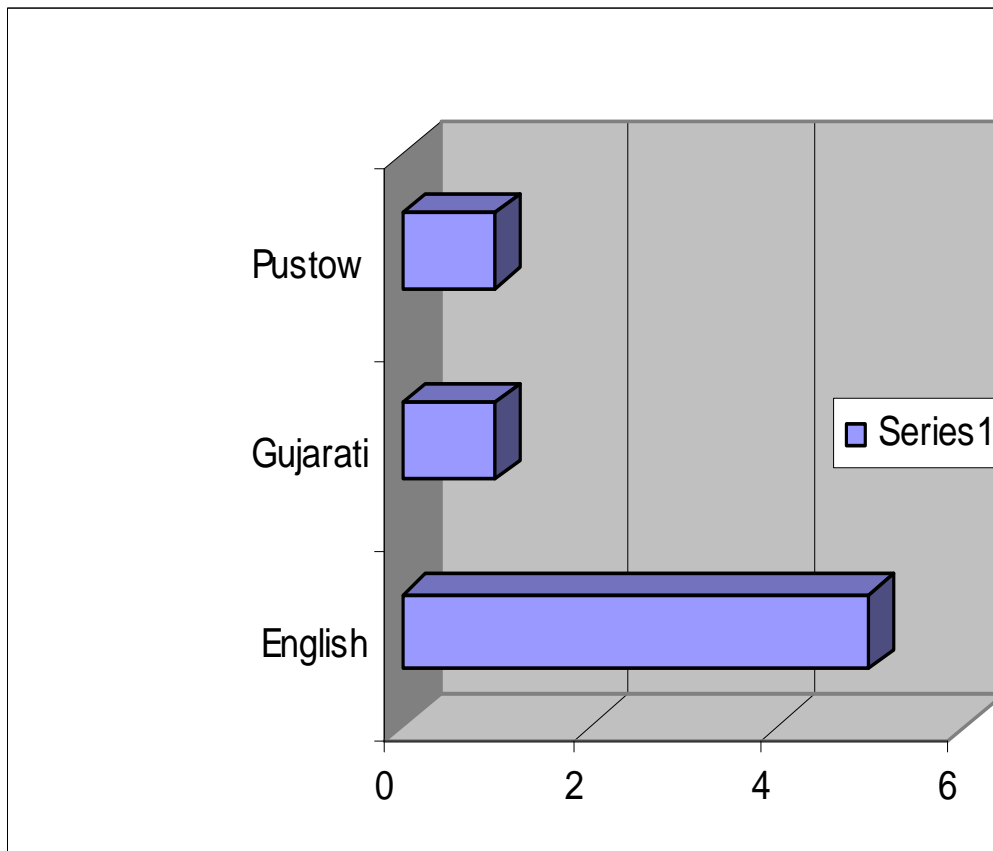
Participants Background

Ethnicity	Gender		Age Range	Sexuality	Disability	Born in UK	Period in UK	Citizenship
	Male	Female						
White British	1		16-18	Heterosexual	Yes (No details)	Yes		British national
Asian Pakistani	1		39-49	Heterosexual	No	Yes		British national
Asian Indian		1	40-49	Heterosexual	Depression & Physical	No	11 yrs or more	British national
Asian Indian	1		39-49	Heterosexual	Schizophrenia	No	11 yrs or more	British national
Black African	1		40-49	Heterosexual	Unavailable	No	11 yrs or more	British national

Graph 1 Participants Religious background



Graph 2 Participants' main languages



Report Findings

This report sets out the findings from the research conducted by mental health service users among service users in Redbridge, North East London Mental Health Trust (NELMHT). It is anticipated that this report will be circulated widely to service users, commissioners and providers so the content, layout and presentation format are intended to make the document easy to read by all.

The report findings are presented in numerical and factual data format, punctuated by actual quotes from the responses given by participants.

For easy identification of participants' personal statements, these are recorded in 21 story episodes throughout the document. They are written in italic font and distinctly presented in text box format.

Below are the results from the discovery interviews held with five (5) service user participants in the pilot study.

1. Knowing something was wrong

One (1) participant admitted using illegal drugs prior to admission, which was a trigger to mental health breakdown and negative consequences.
4 of the participants knew that something was wrong before receiving support.
None of these participants knew where they could get help for their problems and
One (1) participant initially went directly to his GP for help.
One (1) participant did know where to get help but did not seek out that help.

2. Knowing how to get help

Four (4) of the participants said that when they first realised something was wrong, neither they nor their relatives knew where to get help. Two of these participants were eventually taken to the general hospital accident and emergency department from where they were referred to the psychiatric services.
Two (2) participants received help through their GP service and the visiting out of hours Doctor.
One (1) participant was arrested and held in a police cell for some time before being referred to the mental health hospital for psychiatric care.

Episode 1

"Well he (GP) gave me something to calm down. I think some diazepam because I wasn't able to breathe, to calm me down and was getting very anxious and depressed."

Episode 2

"I hadn't done anything you know; I was actually in bed when the police came into the house and they took me to the police station. They took me straight to the police station and put me in a cell, which I think is the worst thing they could have done at the time because I was locked up in a cell".

Episode 3

"When I moved here I was getting – I don't think I got referred to a psychiatrist while I was here because all my information was still coming over to my new doctor. I got registered to a new doctor in Redbridge and I don't think they knew. What happened was, my family didn't know who to get hold of and then my sister found out that there's a psychiatrist or someone at the psychiatric department at the A&E at King George's Yeah".

3. Importance of Information to service users

When asked about the information they received about the care planning process while at the hospital, most of the respondents said they were not given enough information or the information was too late.

Participants identified lack of communication from staff as an issue

Some participants were given no or limited information about their diagnosis.

Most of the participants were not made aware of other services in the community that might be able to help them.

One participant was arrested and held in police cell before receiving mental health treatment

Four (4) of the participants relied on the support from relatives to access psychiatric help.

One (1) participant was given information about available community services

Only one family member (carer) received support (counselling) to help with providing support to the service user.

Episode 4

"Staff did not explain what was happening or anything about the treatment or how long I am likely to stay on the ward or give any information about moving from one place to another".

Episode 5

'I was in three hospitals, one was Goodmayes, one was King Georges, Queens hospital which is a new hospital, the last one I came out of this week'.

"I just was taken in an ambulance one day from Mascalls Park to Goodmayes and yeah that's all I knew of it, that's all I'd hear about.

It was never really explained to me what was happening, what I was doing here or why. No that was never explained to me"

"I didn't know if I was going to a better place or a worse place. I suppose I was hoping it was a better place and in some ways it was. As far as how I felt about it, I was just confused really; just confused as to what was happening to me"

"I haven't had any contact with anyone you know, like a Case Worker or the Home Treatment Team.

I'm not saying I would need to talk to someone like that, but I really would've liked someone to, just someone, like I said, to tell me the options about what I could do, which they didn't."

When I actually came out of hospital, I found out about all the different services that were available

Episode 6

Actually at the end of my period at hospital they told me about the different aspects

Yeah they actually told me before I left, before I got discharged.

So I did actually know before I left hospital.

I was reassured and I was pretty happy.

4. Treatment options

Three (3) of the participants were not offered or made aware of alternative treatment to hospitalisation.

One (1) participant was unclear of the alternatives to hospital that were available.

One (1) participant felt that any alternative to hospitalisation would have been unsuitable for him due to his mental state of mind at the time of admission.

One (1) user received support from the home treatment team, plus counselling and occupational therapy. This participant expressed satisfaction with the counselling service.

(There was no reference to whether or not the counselling was culturally specific and the total number of sessions offered was not taken up).

Episode 7

"I don't think they had any options available. What options are there?"

'I don't think they had an option, because at that time I was so, - my mind was so racing and the things I was saying, and I didn't want to sit still.

I didn't think they had an option to do anything.

I wouldn't have listened to them anyway if they gave me an option'

"Yeah, I was told I have to be in hospital that is the only course of treatment available to me, and my parents couldn't have, they told me they couldn't have me at home, they couldn't deal with me".

5. User satisfaction

Evaluation of service user satisfaction is key to discover what people think and feel about using the service and for providers to assess its perceived quality.

None of the participants in this study indicated whether they were asked by staff to share their experiences or if they were satisfied with the care and support provided by the Trust.

A recommendation within the DRE vision is that service users should be central to the service delivery. Based on the experiences of the participants in this study, the Trust fails to implement the recommendation set by the DRE. It must therefore take steps to involve service user/patients to increase the level of satisfaction among the BME group. User satisfaction can be determined by simply drawing out insights of patients by facilitating focus groups or discussion on the experience of using the service. The Discovery Interview Technique for example, is an effective way to consult patients; but there are other well established techniques for eliciting user views, identifying issues, and measuring user satisfaction.

Participants were asked whether they were satisfied with the care and support they received during their stay at the hospital, and the responses are as follows:

Responses

-“Um no, not really; could have had more help; I think help and support”.

-“I didn't like it because there's nothing to do especially in Goodmayes”.

-“It's a good and a bad place”.

Two participants are satisfied with the service received at the hospital
Three participants are unhappy with the mental health care received from the Trust
Two of the participants expressed satisfaction with the after care services received from community groups such as day centres and the home treatment team.

6. Participants views on hospital mental health services

Four (4) of the participants expressed fear of being in hospital
Three (3) participants were unhappy with the services received at the hospital.

The stories below express the views and experience of participants;

Episode 8

"I think a mental hospital must be the closest place to hell on earth"

*"I didn't like it because there's nothing to do especially in Goodmayes.
I found that there's nothing to do, um, aside from play scrabble with the
Nurses every now and then"*

*"Boredom is the main thing, the main problem, a struggle".
"That frightens me. I was scared and I was confused".*

*"It's a good and a bad place. I mean in a way you're kind of babied, you're given
everything on a plate, all your meals and everything, get your free bed and get a nice
room, get your own space and it was a bit like a holiday from my parents for a while but,
at the same time there were times when it felt like a punishment.*

*"I can't really explain why, I just think, just felt sometimes like I was just being punished.
There isn't really anything else for me to say, I mean, except there's not much to do in a
mental hospital, and it's a weird place to be".*

7. What participants think about care staff

One (1) participant said that "the nurses do not always listen" and refers to a personal physical condition that was repeatedly reported to the nurses, but for which no physical care or attention was received.

One (1) participant thinks that "they did a good job"

One (1) participant said "Could have had more help and support"

One (1) participant said that the aftercare was ok, but was unsure about the hospital care

Episode 9

*"Every Tuesday afternoon there would be the ward round where my Doctor would come on
the ward and he'd have all the Nurses just gather round in a group around him and he'd go
on one side of the room and they'd go on the other side then he'd ask me;
do you think you're getting better?
do you think you're depressed?
do you think you're this, do you think you're that?
do you think you should be allowed to go home soon?
all this kind of thing!
"But I'm not sure he valued my opinion"*

Episode 10

"I didn't feel that the Nurses were always um, would always listen"

"When I was first admitted, um, yeah, to an extent, the food was good, and on the whole the staff were friendly and easy to get along with; but like I said I didn't feel that the Nurses were always um, would always listen. I mean like, I have this problem in my left foot, I have these shooting pains and I eventually got it in my right foot as well; but whenever I'd complained about this to the Nurses they never do anything; they never give me any advice or give me any painkillers or anything; they'd just be like "Oh dear, your foot's hurting".

"It gave me a lot, a lot of grief. I had a lot of sleepless nights because of it".

8. User Involvement

In assessing the participants' involvement in their care and support planning, we looked at their level of engagement in activities on the wards or organised by Trust staff; Also, the information provided to enable participation and involvement in the discharge process. Generally, we found that the level of participation and satisfaction varied according to the amount of information given to them. Most participants felt they had no involvement in the decision making and care planning processes.

When asked if the care planning process had been explained to him, one respondent had this to say:-

Episode 11

"No, no one did. No one explained the situation, what was going to come about like I would have to wait to see someone; that they were going to sort of keep an eye on me for a couple of days, that's what they normally do".

"They keep an eye on you for a couple of days, to see and then they talk to you, the psychiatrist, and find out what sort of things would help you".

"Well, it didn't make me feel very reassured.

It was very confusing, very frightening actually to be in that situation; you don't know what's going to happen, and how long you're going to be kept in that situation for you know; you like to know there's a time when you're going to be let out, you're free to go".

9. Social Activities (on/off the wards)

When asked about the activities available at hospital, the responses were as follows:

Responses

"Yeah, there was time-out group in the OT department, which I went to when I could. There's sports group which was just badminton".

"I think I would have liked it if there could have been more sports played like, basketball and football. I went along when I could to social club and stuff like that, which I enjoyed when I could get off the ward and could go to these types of things".

"I think there should be more activities.

"I think there should be a table tennis table on Thomas Hardy ward because there's one on Pathways. I'd always been looking over to it and getting jealous that they had one and we don't; made me wanna cry sometimes".

"It was just so depressing, you know"

"I had to have someone with me if I want to leave the ward"

"I think a mental hospital must be the closest place to hell on Earth".

"Yeah, that was my experience"

10. About the discharge process

When asked whether they were involved in planning their discharge program from hospital, no evidence of consistency was found in the responses.

The view of some of the participants was that "support planning at discharge had improved". However, most participants expressed the need for more information about options available on discharge and that the information should be provided sooner.

Episode 12

"I was just pleased to be out I would have liked it if maybe as soon as I was discharged I was told about things that I could have done...you know.

I've got someone coming to talk to me about that next week but I would've liked that earlier. But its better late than never...you know.

I'm pleased that I am getting this support. I would have appreciated it earlier but I'm not really complaining".

Episode 13

"Um...a Nurse told me that my parents could come to a meeting with the Doctor and some Nurses and the Doctor told my parents that he was happy to discharge me into their care, which I'd been waiting to hear for quite a while"

Episode 14

"They sat me down in hospital, I said look you know, I come into hospital, I come out of hospital I see a psychiatrist 3 months down the line and there's no support in the middle; then they actually told me no, there is support now! They even told me – I actually saw counsellors and occupational therapist's and other therapist's while I was in the closed ward Pathways, and they actually told me that when you leave hospital there are certain things put in place just for you"

Episode 15

"I wasn't involved in any discharge planning. I was just, I saw the consultant, my sister intervened and said that she was going to look after me or keep an eye on me, I was just told that she could take me home, and I was given my tablets and I was discharged basically, told to wait for the appointment in the post that they were going to send me to see the consultant"

11. Community Services

On the whole service users were happy with support from community services and felt that this had improved over the years.

One participant, however, when asked if he was happy with the information received simply replied "No"

In story 19, one participant tells his story about the information he received about Ley Street resource centre and Mansfield Road drop in centre.

The stories below paint a different picture for each participant.

Episode 16

"I think it's very good. Before when I first came, when I was first ill I thought it was rubbish because the first time I came out of hospital basically all they did was gave me an appointment to see a psychiatrist and he was – the appointment was for 3 months later".

Well, we've got a lady coming to visit us next week to run through a list of options that, you know, things that I could take part in; kind of like community service jobs if you will, not paid work. I don't know what exactly the options are but, but hopefully something. I should be able to find something that I'd be, you know, willing to do, something that would help me pass the time; still a lot of monotony".

Episode 17

"Oh yeah, I got offered the - coz I was quite into the O.T while I was here, we were playing volleyball and stuff like that and I really got into it, and once I told them they said there was a service that I can go to where you can come in once you're out of hospital you can come in and do O.T classes and stuff like that; I can ring them directly. I had no idea that these services existed and the only time I found out is when I came into Redbridge"

Episode 18

"They offered me something else, um counselling they offered me here. I think they asked me if I wanted to come in to counselling, but I didn't take that option because I thought the home treatment and the social worker was pretty good; so they gave me the numbers and I've got the number of my social worker and doctor and his secretary's number. So if at any stage day or night 24 hours a day, if I get in any situation that I don't think I can deal with I can ring someone. After I came out I was put under a consultant as an out-patient you know, and then that was good because I could go and focus on that side of my illness you know, someone to ask me how I felt on that side of things"

Episode 19

"They gave me a leaflet; that's all basically and apart from that I made the initiative move to refer myself you know. They didn't even refer me to this place; I came myself 2 weeks later. I referred myself here and asked if I could come here and that's how I joined this group, because I asked for that, I asked if there was anything in Ilford or anywhere else I said where I live that would help me to get out more you know, and that's how I got that leaflet

I think there is quite a lot of support in this centre, not in many other areas though. I am surprised this centre does offer a lot of things for people. They just sit here and can have food from the menu, can come here for a cup of tea, join little groups like flower arranging to keep your mind occupied you know. When you get depressed you do need something like that to help you get out you know and also to mix with people with similar situations not to talk about being depressed but um mixing with people with similar interests that sort of motivates you. You need to motivate to get you out of depression".

12. Changes in care and support services

When asked whether they had noticed or benefited from any changes in the planning and delivery of mental health care and support, the stories below outline the participants responses.

Episode 20

Definitely, definite improvement. Five years before, say just after the millennium, I don't know whether the referrals and the home treatment were in place or not. But now it's once you get out there's definitely treatment after you get out. That instead of you waiting to get to the part where you get to mania or whatever your illness is and it goes to the stage where you definitely have to get help. You can get help before you actually get to that stage, which is definitely good, especially for people like me.

Basically, I don't want to be arrested by police and put in a cell and stuff like that, and no one knows what's going on basically and the only time they find out is when I've got to the part where I need – when I'm in hospital and they're pulling my records to see who I am and what I've done.

So hopefully this time I'm hoping I don't have to come into hospital because basically the structure's in place where the system will get to me before I get to the part where I need to come into hospital

As I've seen it since August it's a definite change, even inside the system, not just the system where once you leave hospital. There's a definite improvement within the system once you're in hospital. The first time I went into hospital it was like, we'll keep you for a couple of months and then just assign you to a psychiatrist.

It's very different, it's well structured and hopefully it will stay this way. I hope it doesn't go back to the old way because you know it was not very good for us patients

13. What part does racial background play in care and support services?

Two (40%) respondents felt that their race or background was not a factor in the treatment received. The other participants were silent on the matter.

Episode 21

“Um basically the only thing I want to say with regard to race and stuff like that the people you deal with in hospital are professional basically nurses, doctors professional people.

I can't see how they would look at a person and look at his skin colour or race or anything like that. Basically what they look at is your illness and how they can help you basically and that's what I saw when I was in hospital.

I didn't see that a professional person will treat you differently because of your race or colour or where you come from basically”

14. What would participants like from the service

The participants interviewed in this research indicated that they would like to have more information about the care service and about community services before the time of their discharge.

Below is a list of some of the areas that participants would like further information and explanation on while in hospital.

- Most of the interviewees expressed a need to know more about the Hospital procedures, and to have them explained around the time of admission.
- The available alternative treatment options such as ‘home treatment’, which is one area that most of the participants were unaware of.
- Participants would like to be involved more in the discharge process and in deciding activities organised by the wards.
- During the interviews one service user expressed his views about the differences in the activities and equipment on one ward, but which was not provided on other wards. In his view, all wards should equally have a variety of similar activities and equipment.

One participant’s views

“I would like to have been explained to me, the procedures, what would happen like”

- *“who I was with”*
- *“where I was going to be”*
- *“how long I was going to be there for”*
- *“could I contact my relatives”*
- *“could they come in and see me”*
- *“to be freer, like they would treat you as a medical patient”*

15. Conclusion

In general, members of the research team found the consultation process very self satisfying, useful and beneficial personally and for the BME community generally. In particular, two members of the team were awarded distinction by the University of Central Lancashire (Uclan) in the study of Community Based Research. The study also provided interviewees who are themselves user of mental health services the opportunity to directly contribute to the planning and development of the research and ultimately community mental health services in general.

Our experience throughout the research process was that there were clear benefits in using the spine for the Discovery Interview Process in this study.

The benefits of using the discovery interview spine:

- helps to cover the whole journey of the illness and treatment at hospital and in the community;
- triggers significant memories and allows the patient/participant to tell their story in their own way and in their own words;
- allows the patient/participant to remain in control of the ‘interview’, rather than being asked a lot of questions;
- provides rich information that commissioners and providers can use to better understand and plan for the needs of BME groups;
- relates direct experience that cannot be ignored and identified areas for change;
- provides consistency across different interviews by serving as a guide to interviewees.

However, using the Discovery method during the process also presented challenges to the team. For example, by participating in the interview process, service user consultants had to respond to feelings and distress triggered by the significant memory of their personal experience within the system.

As consultants, the wellbeing of the person being interviewed would always take precedence and which makes the interview process even harder for the interviewer and the project team. It is commendable therefore, that user consultants in this study, despite their personal distress, have been happy to carry on with the interviews and have fulfilled their function admirably within the time scale.

Throughout the interview process it was necessary to support interviewers, particularly when an interview had been difficult, or the participant appeared unhappy with the care and support services. In all cases, a 'buddy' system was used where two consultants conducted each interview and provided support to each other throughout the process.

We recognised also that it is possible that by telling their story feelings in participants will be aroused that need to be acknowledged and responded to sensitively. Consequently, the agreed support of the psychology department proved invaluable, as participants who suffer distress as a result of the interview had the option to receive individual psychological support from the manager of the department: however, none of the participants indicated a need for the support from the psychology team.

The findings from the research clearly show that over the years mental health services have improved in some areas. However, participants have also identified areas which require fundamental changes, if service users are to have confidence in the service.

In addition, service users would like changes in some common practices, to be consulted and be more involved in other areas of the delivery of care and support. The following are some areas that the participants feel needs to improve:

- The structure of ward meetings are not user-friendly (it's frightening)
- Staff do not attend to the physical and social needs of patients
- More consideration should be given to patients' holistic needs; including family, pets and household bills etc.
- Patients should have more information about hospital procedures, (e.g. information on diagnoses and treatment)
- There should be no differences in the activities provided on the wards
- Patients feel that they are not consulted about activities on the wards
- A wider variety of activities should be available for patients
- Patients do not like being moved from one hospital to the next, or between various wards or from one locality to another.
- Where movements are necessary patients should be told in advance and given adequate information.

The consultation process was affected by the lack of full accurate ethnicity monitoring record from the wards at Goodmayes. In preparation for the discovery interviews, we requested from the wards a breakdown of the languages spoken by BME patients, but this information was not available from any of the wards.

Staff should therefore ensure that language is among the data collected from patients during the admissions process.

Finally, the good work of the Trust as acknowledged by some of the participants should be recognised and continue as these have clear benefits for the patients.

Based on the experience of the participants in this research, there has been obvious progress in the provision and delivery of mental health services, both in hospital care and community support.

The point is clearly expressed by one participant accordingly:

“As I’ve seen it since August it’s a definite change, even inside the system, not just the system where once you leave hospital. There’s a definite improvement within the system once you’re in hospital. It’s very different; it’s well structured and hopefully it will stay this way. I hope it doesn’t go back to the old way because you know it was not very good for us patients”

Recommendations

There are a number of steps that can be taken to help address the issues raised by the service user participants in this report. The following are our recommendations:

1. Ward (consultation) meetings

Commentary

Participants in the study have expressed how frightening they find entering a mental health hospital and the structure of ward meetings very fearful.

This was an issue raised by the DRE and the implementation of the recommendation would go a long way in helping to deal with the matter. In their recommendation the DRE stated “Encouraging a member of the family, community or friend (with expertise in translation if necessary) to be present during the first interview can help to ease a patient into care”.

- Ward managers should ensure that the experience of patients at the point of admission is more pleasant and welcoming and that ward meetings user-friendly.
- Ward meetings can be more user-friendly simply by rearranging the layout of the room in a less formal way and perhaps providing refreshments etc for participants.

2. Holistic patient care and support

Commentary

Some service users have reported that care and support received on the ward take no account of their physical health or social needs. One participant mentioned reporting to staff the symptom of having chronic pains in his legs, but staff responded in a patronising, sarcastic way rather than offering advice or help.

- Ward managers and staff should seek to attend to the physical as well as mental health and social needs of patients.
- As part of the package of care, at the point of admission consideration should also be given to the patient’s day to day issues such as health & safety at the patient’s home, e.g. is their home secured for the duration of their admission, care for house pets, payment of household bills etc.

3. Information to patients (DRE recommend better information)

Commentary

Generally, participants said that they did not have sufficient information at the right time during the period of their admission. Listed below are areas that participants would like managers to provide information on:

- Staff to explain to service users hospital admission and care policies and procedures (e.g. information on diagnoses, treatment options, duration of admission etc)
- Service users should be given relevant information of services before discharge.
- The use of advocates or relatives should be encouraged to support patients at the traumatic and critical time during the admission process.
- Commissioners should ensure that the public has sufficient information where to get help during a mental health crisis. It is clear from the experiences of participants that some BME service users and their family members did not know where to get help or the process.

4. Social Activities

Commentary

Participants would like more and varied activities on the wards; also that the activities on one ward is the same on all the wards.

- Managers should consult service users more widely about activities on the wards or organised by trust staff.
- Ensure that activities provided on one ward are common to all the wards.
- Provide a wider range of activities on the wards
- Providers should seek to maximise services provided by community and voluntary sector services such as CVP, Psychology, Counselling and day care services

5. Less movement of patients between hospitals, various wards and locality

Commentary

One participant reported during the interview process of being moved across three hospitals within a short period, without prior consultation or information relating to the moves.

- Providers should seek to limit the movement of service user/patients.
- Where relocation is necessary, this should be communicated to patients and carers and clear information given in support of the move.
- Providers should monitor and improve communication between services in different areas, wards and across services to ensure a seamless service for patients.

6. Care & Cultural Background

Commentary

The participants to this study said that culture and background did not feature in the planning or delivery of care and support received. This may be because staff treat every service user in the same way without having regard to individual cultural needs.

- Staff should be trained in how to provide culturally sensitive care to BME patients.
- Staff should record the languages spoken by BME patients as part of the data collected from patients during the admissions process.
- All services should be culturally appropriate and sensitively delivered

7. Appropriate and responsive service

Commentary

Only one of the five user participants was offered alternative treatment. One respondent said “I didn’t know that there were alternative options available”. Most of the participants interviewed express fear of the hospital and confusion particularly during admission.

- BAME patients should be offered alternative treatment such as Home Treatment, Talking therapies and OT services
- Staff to inform patients of the alternative treatments available as soon as possible to enable informed choice
- All patients during admission and observation period should be given full explanation of their level of care and support during that period.
- Where necessary appropriate medication or culturally sensitive talking therapies should be offered as alternative to all patients to alleviate fears.

8. User satisfaction

Commentary

Participants in this study were not consulted on their level of satisfaction of the care and support received.

- Providers should routinely consult patient/service user on their views of the service
- Providers should monitor activities on the ward, including CPA and community meetings to assess quality standards of the service

9. Routes into hospital

- Providers should monitor and record the access routes of BME patients into hospital

Appendix 1 **Discovery Interview Spine**

Thursday 23rd November – Training Discovery Interview Spine

1. How long has it been since you were in hospital?

2. Worrying that something was wrong.

- Before you came into hospital, were you worried that something was wrong?
- Did you know where to get help?

3. Talking to someone about getting help.

- How did you get help?
- How did you obtain that help?
- Who did you talk to? (e.g. GP, family, friends, etc)
- Did someone talk on your behalf? (e.g. participant may have been sectioned)

4. Receiving help from services.

- What options were offered to you? (i.e. alternatives to hospital admission)

5. Understanding of what would happen next.

- Did you understand what was going to happen next?
- How was it explained to you?
- How did that make you feel?
- Where was this explained to you?

6. Getting ready to leave hospital.

- How were you involved in your discharge planning?
- Did anyone help you?

7. Settling back into the community.

- Can you tell me about the support you received from services?

8. Help and support.

- Looking back at when you were admitted and discharged, are you happy with the level of help and support that you received?

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