

COMMUNITY ENGAGEMENT PROJECT:

The National Institute for Mental Health in England

Mental Health programme

*Report of the Community Led Research Project Focussing on
Male African and African Caribbean Perspectives on Recovery*



BY Southside Partnership Fanon with support from the Catch-a-Fiya survivor network community in Lambeth and Southwark
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FOREWORD



Our ambition as an organisation is to deliver services that are person-centred, culturally competent and recovery focussed. There are no shortcuts for us in realising this ambition, but we have embarked on a series of initiatives with users, staff and partners that we believe will help us to take increasingly confident steps towards this goal. This piece of research represents one of those initiatives and includes a number of recommendations that will help us to move towards our goal.

Recovery means different things to different people. No two experiences of recovery or illness are ever the same. Listening to the personal stories of the participants in this research we have been struck by the uniqueness of each story, yet simultaneously by the common themes that have emerged as participants have in their narratives of illness and recovery frequently identified common barriers, common factors that facilitate recovery and shared concepts of mental illness and recovery.

The ambition of all good mental health services must surely be to identify and address these common barriers, and to create the conditions for recovery to routinely flourish.

This research has focussed on the experiences of African and African Caribbean men using mental health services. Our organisation, like most others, continues to try to deliver better, more appropriate services to these men. If the findings are anything to go by, then what African and African Caribbean men say matters to them as they strive to recover their lives, 'are quite ordinary; human things that everyone aspires to have.' There can surely be no greater invitation for us to act on this, nor a greater indictment that we have not so far.

The challenge we have set ourselves on completion of this research is to act on the recommendations. With the continued support of partners, service users and our staff, this has begun.

Nicholas Campbell-Watts
Director of Fanon.

Recovery Project Team

Milton Brown

Milton was a Volunteer Community Researcher since the beginning of the project and until September 2007. He is a devoted practitioner and exponent of Rastafarianism.

Belonwu Enzenma

Belonwu was the original Community Research Coordinator for the Recovery Project, working alongside Guilaine Kinouani in leading the Volunteers along the path of the research. He provided training in conducting Interviews and Focus Groups, and led discussions on Recovery.

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Pel has worked as a volunteer at Fanon since April 2007. Having come from an Employment and Housing for disadvantaged people background, Pel now volunteers at Fanon on reception and teaches service users basic computer skills. In his role as a researcher on the Recovery project, Pel learnt about equality and diversity and the Delivering Race Equality Agenda (DRE).

Pauline Etim-Ubah

Pauline has a background in the arts having studied Art and Design at the University of the Arts London and also Cultural Policy and Management at Birkbeck University. She has worked in various arts development roles in organisations across the public, private and voluntary sector. Pauline is a trustee at Cooltan Arts, a local mental health charity where she had previously been a volunteer and Communications Officer and became a Community Development Worker at Fanon Resource Centre in February 2008.

Merline Gabriel

Merline was a Community Researcher on the Recovery Project from October to November 2007. She was instrumental in conducting a number of interviews, giving out questionnaires, and analyzing the data from the interviews. Merline also works at Fanon House as a project worker.

Tim Hobbs

Tim was a Volunteer Community Researcher from the beginning of the project until September 2007. He has been a long-term active contributor to the MIND (National Association for Mental Health).

Lloyd Lindsay

Lloyd is an artist who has interest in drama development and achieved a 2:1 degree in the Arts. He was an integral part of the Recovery Project from its start until November 2007, acting first as a Volunteer Community Researcher, before being promoted to Community Research Co-coordinator on the project. He is devoted to using his learning to empower service users in their quest for identity and recovery.

Guilaine Kinouani

Guilaine was Community Development Worker for Southside / Fanon when she initiated and designed the Recovery project. Her background is varied and she is currently working towards the completion a PhD in Cross-Cultural psychology.

Elicia Mollineau- Angoy

Elicia joined Fanon Resource Centre in April 2006 as a Project Worker and progressed to Team Leader in 2007. She was appointed Community Development Team Leader in February 2008 and is extremely pleased to be working on the Recovery Project. Elicia is dedicated to working towards the improvement of the treatment and care received by African and African Caribbean people within the mental health system and is currently pursuing an MSc. in Mental Health Studies at King's College, London.

David Pinder

Having trained as a Carpenter and Joiner, he has spent 20 years working in Africa, setting up vocational training schools and village polytechnics. This led to a position in the Ministry of Education developing appropriate national curricula and assessment procedures. Recently, he was employed by Southside / Fanon as the Life and Work Skills trainer developing vocational and work placement opportunities for service users. Since February 2008 he has been working as a Community Development Worker for Southside/Fanon. He is currently studying Social Policy at London Southbank University.

Alexei Weig

Alexei's background is in the sciences and engineering, but his interests lie mainly in diverse views of spirituality, and he has travelled throughout India and Nepal. Since July 2007, he has acted as a Volunteer Community Researcher, then as a Community Research Co-coordinator throughout the life of the project. He is committed to the collective improvement of mental health services in London.

Ian Wint

Ian trained as a steel fabricator working for various metal work establishments in South London. He developed an interest in working with young people as an opportunity to put something back into the community. He gained a position as a youth worker which led to a role as a project leader working with NEET young people (Not In Education, Employment or Training). Having established himself as a project leader he has since progressed and is now a Community Development Worker for Southside / Fanon.

Abdigani Yussuf

Abdi's background is Health Promotion and he has worked in the Substance Misuse and Mental Health field for a number of years in both specialist and generic services. Abdi's most recent work, prior to being appointed as a CDW, was being the lead researcher involved in Lambeth's Qat Report (2007) done in partnership between Safer Lambeth, Fanon, and the local Somali Community organisations. Abdi is also one of Lambeth's Community Advocates and is very passionate in his CDW role.

ACKNOWLEDGEMENTS

We are indebted to the many service users who have made this project a reality by volunteering their stories and insight. You are all inspirational to us and we could not thank you enough. We accept this report does not begin to do justice to the complexity, and power of your accounts but we hope this attempt will capture some of the key ideas you have mentioned.

Special thanks to Joanna Hicks UCLan (University of Central Lancashire) and Chandra Fowler NSUN (National Survivors User Network), for taking the time to review our research material and for their invaluable contributions to the final report. We would also like to state that the (DREEM) Toolkit – Developing Recovery Enhancing Environments has played an integral part in forming the basis for our research and for this we would like to acknowledge the work of Piers Allot- Emeritus NIMHE National Fellow for Recovery, Mike Slade – Institute of Psychiatry and Hugh Middleton – University of Nottingham. The extent of your work and material you have contributed to Recovery and the roll out of DREEM in the UK is excellent.

We greatly appreciate the support from Denise Bobb (DRE), Patrick Gillespie (SLaM), Denis O'Rourke (Lambeth Primary Care Trust), Kamel Chahal (SLaM).

We would like to take this opportunity to show our gratitude to the local BME voluntary organisations in Lambeth and in Southwark for their enormous support, including Dominic Walker (Catch a Fiya), Paul Asquith DAAT (Drug and Alcohol Team).

Finally, thank you to Guilaine Kinouani and Belonwu Enzenma for the initial groundwork and to everyone at Fanon for their dedication in completing such a vital and much needed piece of research.

Thank you all.

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Executive Summary

Fanon is a charitable organisation that provides culturally specific services that support black and minority ethnic (BME) communities experiencing mental health issues. Projects focus on developing innovative services, reaching new communities, supporting people to develop self help and independent living skills and establishing links with a range of organisations and agencies to increase the opportunities and choices available to Service Users.

The project was started in spring 2007 by the first Community Development Worker (CDW) supported by a team of volunteers who became Community Researchers and a Community Research Coordinator. The majority of the Community Researchers moved on from the project at the end of 2007. A new team of CDW's were appointed and subsequently worked alongside a Community Researcher from the previous team to complete this project.

The London Borough of Lambeth is an area with an estimated population of 266,169 people from diverse backgrounds. This group is made up of 62% White British and 38% BME (Black and Minority Ethnic) communities, which includes 12% African Caribbean and a further 12% African. This is significantly higher than the London and UK averages. Lambeth is seven miles long, three miles wide and is made up of twenty-one wards, sixteen of which are amongst the most deprived in England. Lambeth is made of five town centres, North Lambeth, Streatham, Clapham and Stockwell, Norwood and Brixton. It is one of the most densely populated of all the inner London boroughs. It is little wonder then that within this diverse community there are at least 150 different languages spoken. For the purpose of the research, the majority of participants were drawn from in and around Brixton. Brixton is recognised for its multi-cultural and vibrant communities.

Research Aims

The Recovery Project looks at African and African Caribbean male Service Users' perspectives on Recovery. We are hoping that this unique insight into what Service Users think and feel about the processes of Recovery will positively impact on mental health provision in Lambeth. We aim to validate the experiences of Services Users,

many of whom feel they are not listened to and do not have any (significant) input into their Recovery. We hope that the findings will impact on the services in Lambeth in the long term.

Most services that work in this area agree there are numerous definitions and concepts of Recovery. However, there seem to be some common themes inline with NIMHE's (National Institute for Mental Health in England) guidance such as those provided by services like SLaM or SPN (Social Perspectives Network). Clarity about the concept of Recovery and its theoretical and evidence base is necessary for four reasons:

- Partnership: the new lynchpin of health policy
- User involvement and citizenship
- Focus on the multi-determinants of health
- Clarifying the evidence base

These relate to the underpinning influences and characteristics of the Government's approach to reforming health policy and services which has been evidenced over the last decade. This will enable a more inclusive and collaborative, people-centred approach to delivery of services.

Currently, these developments and other initiatives offer a number of opportunities to integrate both the theory and the practice of Recovery into services and effectively address mental health challenges.

Our specific aim:

What can be learnt from the perspectives of male African and African Caribbean Service Users to inform the design and delivery of mental health services in Lambeth?

Research Design / Methodology

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. 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.

The research focussed on male African and African Caribbean Service Users as they were found to be over-represented within mental health services, in some cases 4 – 6 times more likely than their white counterparts.

- What do Services Users consider to be the barriers to their recovery?
- What factors do Services Users think facilitate Recovery?
- How do Service Users conceptualise Recovery and what does Recovery look like to them?

Our research demonstrates Fanon's commitment to implementing the three building blocks of DRE:

Community Engagement

The participation of Community Researchers and local BME organisations, allowed for real community ownership of the project and its outcomes. By using Community Researchers to collect the evidence for this research, we are facilitating important shared learning amongst service users, the wider BME community and the statutory sector.

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.

Better information

This report seeks to add another dimension to the existing material produced on Recovery. This is the first paper of its kind focusing on the experiences of African and African Caribbean men and their pathways to Recovery. By using their stories, we are able to put forward examples of the social, environmental and cultural factors which may contribute to Recovery.

Appropriate and responsive services

By disseminating the findings we anticipate a significant impact on how services respond to the needs of this particular ethnic group. Service users will engage more productively with services that recognise their ideas of Recovery.

This project is a combination of both qualitative and quantitative approaches and we adopted two methods of data collection to obtain the necessary information. The following tools were used:

- Semi-structured Individual interviews (see Appendix III)
- Questionnaires (see Appendix II)

A semi-structured interviewing technique was used as a qualitative data collection method where interviewers asked set questions. In total twenty-two, one to one interviews were carried out with each one lasting about one hour. The quantitative data was collected using questionnaires which included a set of core questions comprising age, demographics and ethnicity. A total of seventy (70) were distributed to the target group.

Analysis & Findings

The audio-tapes from the interviews were transcribed externally by OUTSEC. OUTSEC Limited provides an outsourced typing service for individuals and companies needing transcription of dictated sound files. A total of twenty-two (22) interview scripts were returned. The qualitative data from the interviews were thematically analysed in relation to emerging themes of Recovery, specifically (but not limited to): Barriers; Conceptualization and Facilitating Factors. To ensure inter-rater reliability or concordance of the transcript's contents, each interview was read once by two different

individuals. The questionnaires were also externally analysed by NSUN using SPSS (Statistical Package for Social Sciences).

Barriers to Recovery

Stigma emerged as a common barrier to recovery amongst the respondents. Many of the respondents indicated that negativity from family, friends and society is unhelpful in their journey of Recovery. A number of these respondents described becoming trapped by stigma and stereotypes as similar to a self-fulfilling prophecy. Consequently, this negativity has a ripple effect on personal relationships. Participants viewed a breakdown in personal and family relationships as a contributory factor to the lack of support required to sustain them on the road to Recovery.

Facilitating Factors

Having a family and support network is seen as the main facilitating factor by all participants in this study. The care and support of loved ones is significant to Recovery as respondents believe that having a safety net and knowing that someone is there to help them through the difficult times, is extremely important. Some respondents viewed employment and education as a major facilitating factor in Recovery. The idea of being 'normal' by having a job or attaining further qualifications to enter the world of work is a stabilizing force for many Service Users.

Conceptualisations of Recovery

The majority of respondents stated that Recovery is 'being able to move forward, have a positive outlook on the future and live independently'. Many of the respondents expressed an interest in taking up employment and education, which they felt would enable them to give back to their communities and contribute to society again: "*I'm alright now, let's see who else I can bring up.*" Many respondents believed that Recovery also involves developing confidence, a sense of self-worth, being treated equally, happiness and the ability to stay in control and sustain one's well-being.

Over a quarter of respondents spoke of spirituality as having a positive impact on their pathway to Recovery. The knowledge that there is a higher power within the universe and having a strong sense of faith was a source of comfort and support for many during periods of crisis. Another facilitating factor for several of the respondents was developing a routine. This included attending local community organisations, exercise and leisure activities.

Causal and Contributory Factors of Mental Illness

Many respondents shared their thoughts on their pathways into the mental health system and what they identified to be some of the causal factors. These are a combination of social and financial aspects. The majority of participants interviewed and those who completed questionnaires have been using the mental health service for more than 5 years, with a significant number of the respondents having accessed mental health services for 10 years or more. Some of the respondents adopted various ways of managing or coping, including an acceptance and understanding of their own mental ill health. Others were keen to discover alternative ways of managing their mental ill health and progressing along pathways to Recovery.

Recommendations and Strategies

The findings generally indicate that the focus of recommendations should be on prevention as opposed to cure and by looking at opportunities to address some of the bio-psycho-social issues we may go some way to understanding how to deliver practice that echoes this. Through cross-agency working and practical partnerships service users will be able to access a range of provisions that more closely serve their needs. This will need to take place in an environment where statutory and voluntary organisations are consistent in what they say about Mental Health and which reflects the objectives of the 'Delivering Race Equality' agenda. The following recommendations arise directly from the project findings and take in to account the actions that need to be taken at the grassroots level – practitioners and service providers, strategic level – commissioners and policy makers and an illustration of the impact if they are followed through for service users (see main body of report):

1. Being able to contribute to society

- Mental Health services should show a commitment to volunteering schemes that give service users some responsibilities (where appropriate) in the services they attend.
- Make service users feel empowered and give them some ownership into the service that they receive.

2. Awareness of Mental Health in the Community

- Produce Mental Health guides that include accessible (possibly culturally specific) language that explain the different terms used in mental health:
- Mental health professionals should work with community organisations to develop clear explanations of mental health terms

3. Learning and Education

- Mental Health services to bring in or make links with organisations that have expertise in education and training to develop partnerships, projects, models of working so that service users have the opportunity to return to Learning.
- Service users should also be allowed to evaluate any opportunities they take up to inform future service delivery.

4. Faith and Spirituality

- Mental Health Services should use more faith-based organisations and their facilities for events and activities.
- Mental Health Services should work with Faith Leaders to develop a training programme for front line staff about the different beliefs held by BME service users

5. New Skills and Workability

- Employment that slowly integrate people back into the workplace and provides in-work support.
- Mental health agencies working together with employers to promote positive images of people with mental health issues
- Designated staff in the workplace that are trained in mental health issues that can act as mentors

6. EARS (Empathy and Advice, Responding with Support)

- Mental Health Services in Lambeth should set up or link into existing service user forums;
- Mental Health Services should develop more effective ways of communicating with service users
- Services should recognise the importance of peer support in a service users' long term Recovery

7. Alternatives to Medication

- Monitoring on the outcomes of services users that participate in regular leisure activities (arts, sport, music, cooking etc.)
- Lambeth PCT should commission a study on the alternatives service users use to aid their recovery. What are these alternatives and what are the benefits and effectiveness of them?

8. Cross – Agency Working

- Cross-Agency wide toolkits and training packages developed to educate service providers about other services
- Joint working with Criminal Justice, Substance Misuse, Social Services, Housing and Benefits
- Service users are treated holistically with all issues (bio-psychosocial approach) taken into account

9. Representation of African / African Caribbean Women in the Mental Health Service

- A longitudinal study into the experiences of women in the mental health services that would highlight the cause and effect of mental ill health and demonstrate potential pathways to Recovery.
- Further training for staff at local services so that vulnerable and hard to reach women are referred to mental health services as early as possible.

It is our hope that these recommendations will be the beginning of a process of reform not just in the delivery of mental health services, but also in the commissioning, development of legislation and accessing of mental health services for African/ African Caribbean communities in Lambeth.

INTRODUCTION

Fanon is a charitable organisation that provides culturally specific services that support black and minority ethnic (BME) communities experiencing mental health issues. Fanon was established in the early 1990's and joined with another charity, Southside Partnership, in 1999 to form the Southside Partnership Group. Our projects focus on developing innovative services, reaching new communities, supporting people to develop self help and independent living skills and establishing links with a range of organisations and agencies to increase the opportunities and choices available to Service Users.

This research project was started in spring 2007 by the first Community Development Worker (CDW) supported by a team of volunteers who became Community Researchers and a Community Research Coordinator. The Community Researchers were instrumental in developing the project, gathering and analysing the data. The majority of the Community Researchers moved on from the project at the end of 2007. A new team of CDW's were appointed and subsequently, worked alongside a Community Researcher from the previous team to complete this project.

The Recovery Project looks at African and African Caribbean male Service Users' perspectives on Recovery. We are hoping that this unique insight into what Service Users think and feel about the processes of Recovery will be able to impact on mental health provision in Lambeth. We aim to validate the experiences of Services Users, many of whom feel they are not listened to and do not have any (significant) input into their Recovery. We hope that the findings will positively impact on the services in Lambeth in the long term.

The National Context

There were approximately 80 projects supported by The National Institute for Mental Health in England (NIMHE), some of which took place in London. Two of the projects included the experiences of adult mental health Service Users in Tower Hamlets and the impact assessment of the Mental Health Guide Programme on BME communities in Hackney.

This is a period of major change in the way services for people with mental health issues are developed, planned and delivered. The National Service Framework for Mental Health in 1999 and the NHS Plan of 2000 put the improvement of mental health services at the top of the government's health agenda. The current move to establish joint Social Care and Health Care Trusts is accelerating the integration of service delivery and the challenges of joint working. There has been concern that with these widespread changes some of the very skills, knowledge and attitudes valued by Service Users may be swept away by introducing uniform models of service delivery. As mainstream services are beginning to come to grips with having a more holistic approach to delivery of services they are actively looking for relevant frameworks to underpin these approaches.

Most services that work in this area agree there are numerous definitions and concepts of Recovery. However, there seem to be some common themes inline with NIMHE's guidance such as those provided by services like SLaM or SPN. One of the recent initiatives has been the Letting Through Light (LTL) project, as part of this wider movement towards better practice. Both the principals and the approach that lie at the heart of the LTL's materials can be applied and used right across all mental health services. Indeed, several areas are adopting the LTL materials as a core part of their service training. The training presents a positive image of black mental health Services Users as survivors of the system, not victims.

Clarity about the concept of Recovery and its theoretical and evidence base is necessary for four reasons:

- Partnership: the new lynchpin of health policy
- User involvement and citizenship
- Focus on the multi-determinants of health
- Clarifying the evidence base

These relate to the underpinning influences and characteristics of the Government's approach to reforming health policy and services which has been evidenced over the last decade. This will enable a more inclusive and collaborative, people-centred approach to delivery of services.

Currently, these developments and other initiatives offer a number of opportunities to integrate both the theory and the practice of Recovery into services and effectively address mental health challenges.

Devon NHS Recovery Programme

A lot of useful guidance has been drawn as part of Devon's Recovery competence such as: the importance of listening to the person, self management and autonomy, social inclusion principles, as well as how services and approaches can help or hinder Recovery. On the other hand Devon's Recovery services have what is known as an STR Worker (Support Time and Recovery Worker).

One of the approaches adopted by Devon's mental health services is the WRAP model (Wellbeing Recovery Action Plan) which was created in 1997 by American Mary-ellen Copeland. WRAP is not a "one size fits all" approach and each organisation's WRAP is unique.

However, there is no specific mention of people's cultural and spiritual importance which all modern mental services should have in the pluralist approach supported by the Department of Health's agenda in the White Paper.

South London & Maudsley Trust (SLaM)

Some of the principles used by SLaM to promote recovery include:

Recognising that medication is an element of many pathways in Recovery and not the whole solution; offering some hope to Service Users; recognising culture, ethnicity, sexuality and spirituality; recognising that family and friends have essential roles and expertise; engaging with outside agencies; assisting Service Users to make choices about their lives; carrying out risk management; engaging with local communities and playing a positive role, as well as promoting mental wellbeing.

The Recovery strategies presented here do not address or emphasize much about the Recovery competency of the communities who already find it difficult to engage with the traditional statutory sector services. In the case of faith communities, a wide range of evidence and knowledge is emerging that mental health services should not see the community mental health teams as the absolute solution to the mental health needs of patients. This evidence suggests they should incorporate other aspects including spirituality as well as support from friends and families in a Service User's care plan. A stronger partnership is needed between the statutory agencies, voluntary organisations and faith communities so as to ensure that individual' spiritual needs are being recognised, thus making the services more client-centred.

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

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 (DAT's). 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 Aim higher.

The key ingredients of the model

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

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

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

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

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.

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

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

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

The steering group is an essential element of the project: it helps the community researchers to identify the community they are engaging with, and can also facilitate the long term sustainability of the projects recommendations and outcomes. The community researchers undertake a needs assessment or a consultation exercise. However the

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

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

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.

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

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 DAT's 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 DAT's 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 DAT's 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.

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

Our specific aims

What can be learnt from the perspectives of male African and African Caribbean Service Users to inform the design and delivery of mental health services in Lambeth?

The research focussed on male African and African Caribbean service users as they were found to be over-represented within Mental Health services, in some cases 4 – 6 times more likely than their White counterparts. Our research focuses on the following themes:

How do service users conceptualise Recovery and what does Recovery look like to them?

Recovery can be a relative concept and not a universally agreed term. It can have different meanings within similar groups of Service Users. Therefore, it is important that we understand how the Service Users with whom we work, think about what Recovery actually means to them. This could be one way of supporting those who are experiencing mental health issues. If we are able to comprehend how individuals or collective Service Users view Recovery, then services may be able to offer them more appropriate support through their journey of Recovery.

What do services users consider to be the barriers to their recovery?

There are some challenges which prevent service users from accessing statutory services, especially mental health services. Therefore, it is important for all the services to understand the existing barriers. This will enable services to respond appropriately and improve service delivery at every level. Some common barriers include: a lack of culturally sensitive approaches; language barriers; fear; stigma;

discrimination and institutional racism. Several of these obstacles can be overcome with the adoption of various models of engagement, Service User involvement, training and other recommendations proposed by the DRE action plan.

What factors do Services Users think facilitate Recovery?

As there is no agreed concept of Recovery, it follows that there is no single approach in facilitating Recovery. Consultation with mental health Service Users enables their contributions to be implemented thus improving service delivery. Historically, health professionals have dictated the pathway to Recovery for Service Users. However, this research will focus on the real experiences and perspectives that describe their pathways to Recovery.

Links to Delivering Race Equality (DRE) in Mental Health Care

Our research demonstrates Fanon's commitment to implementing the three building blocks of DRE.

Community Engagement

The participation of Community Researchers and local BME organisations, allowed for real community ownership of the project and its outcomes. By using Community Researchers to collect the evidence for this research, we are facilitating important shared learning amongst service users, the wider BME community and the statutory sector. Due to the fact that participants were interviewed by fellow Service Users, the evidence has a greater integrity than it would have otherwise. Service Users were given the opportunity to talk to their peers, who empathised with their experience in a way that health professionals may not have been able to. Service Users felt more able to be honest and speak freely. Therefore, we feel that the evidence more closely reflects their views and experiences of Recovery. This provided us with information that can be used to influence mental health policy. Working in partnership with the community and the statutory sector is vital to sustaining the outcomes and recommendations of this report and also a good starting point for the work of the CDW's.

Better information

This report seeks to add another dimension to the existing material produced on Recovery. This is the first paper focusing on the experiences of African and African Caribbean men and their pathways to Recovery. By using their stories, we are able to put forward examples of the social, environmental and cultural factors which may contribute to Recovery. The data collected and the methods of collection will contribute to improving the monitoring of ethnicity in mental health services. A combination of qualitative and quantitative methods has been employed in this research. The findings will provide a holistic and culturally sensitive approach to Recovery.

Appropriate and responsive services

By disseminating the findings we anticipate a significant impact on the ways that services respond to the needs of this particular ethnic group. Service Users will engage more productively with services that recognise their ideas of Recovery. This report will go some way to starting legitimate dialogues between Service Users and the statutory sector, working towards providing services where they feel valued and appropriately represented.

What does Recovery mean?

The term 'Recovery' is a subjective one and a relatively new concept applied to mental health. Research into the concept of Recovery developed in the mid-1980's. Both health professionals and Service Users were keen to move away from the model of serious mental illness being chronic or permanent. In order to put our Research into context we have provided below some (but by no means definitive) explanations as to what Recovery might mean. NIMHE has defined Recovery as *"a personal process of overcoming the negative impact of diagnosed mental illness despite its continuing presence"* and *"a process of changing one's orientation and behaviour from a negative focus on a troubling event, condition or circumstance to the positive restoration, rebuilding, reclaiming or taking control of one's life."*

Patricia Deegan was one of the first Service Users to put forward a concept of Recovery:

“Recovery refers to the lived or real life experience of people as they accept and overcome the challenge of the disability ... they experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability.”

One definition that provides a robust description of Recovery has been put forward by William Anthony, Director of the Boston Centre for Psychiatry and Rehabilitation:

“...A deeply personal, unique process of changing one’s attitudes, values, feelings goals, skills, and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.”

For the purpose of this report we do not seek to add another definition of Recovery to the myriad examples that exist. We intend to share the experiences of Service Users and put forward recommendations on Recovery. It will be interesting to see if there are any comparisons or gaps between the academic/medical models of Recovery and the beliefs/experiences of the Service Users we interviewed.

Our mission statement is *“Supporting people from black minority ethnic communities to lead independent lives”*. This is reflected in our day to day practice. The consensus of the organisation is that Recovery means becoming empowered by gaining an understanding, of who you are, recognising the contributing factors to your mental well being and learning the skills needed to manage, overcome or change your personal situation. Perceptions of Recovery can be about a reduction in the effects of a ‘condition’ or ‘diagnosis’ but also being more motivated, enjoying life and being able to contribute to the wider community. Fanon see its role as supporting Service Users to regain independence and develop a positive outlook on life. This is possible when someone is able to take responsibility for their own mental health.

Background

The London Borough of Lambeth is an area with an estimated population of 266,169 people from diverse backgrounds. This group is made up of 62% White British and 38%

BME communities, which includes 12% African Caribbean and a further 12% African. This is significantly higher than the London and UK averages.

Lambeth is seven miles long, three miles wide and is made up of twenty-one wards, sixteen of which are amongst the most deprived in England. Lambeth is made of five town centres, North Lambeth, Streatham, Clapham and Stockwell, Norwood and Brixton. It is one of the most densely populated of all the inner London boroughs. It is little wonder then that within this diverse community there are at least 150 different languages spoken. For the purpose of the research, the majority of participants were drawn from in and around Brixton. Brixton is recognised for its multi-cultural and vibrant communities.

Lambeth has a high rate of unemployment compared to the rest of the country, as shown by the following table (T1). Despite this, 37% of households are owner occupiers and the borough is home to some 9,800 businesses providing jobs to some 119,400 people.

T1. Unemployment percentages for Lambeth, London and England

	Lambeth	Inner London	England
<i>Unemployed (%)</i>	9.8	8.9	4.8

At present Lambeth has the highest levels of teenage pregnancy in the Europe (number of conceptions per thousand females age 15 to 17) and the highest rate of HIV infection for the whole of the UK. In addition, levels of homelessness, drug misuse and violent crime are all above both regional and national averages.

For the purpose of the research, the majority of participants were drawn from in and around Brixton. Brixton is recognised for its multi-cultural and vibrant communities. Many people will know the area for its entertainment scene, leisure activities and many restaurants and the famous Brixton Market.

A quote from a former resident recalls:

“As a young boy one of my earliest memories of Brixton is the market. I can remember only too well the countless occasions where I would be left holding part of the weekly

shopping while my mother continued endless conversations with the many people she knew who also shopped there.”

This particular part of Lambeth has been hugely significant due to its rich history as a Mecca for people of colour who arrived in the UK in the 1940's and 1950's.

Life expectancy in Lambeth has been consistently lower than the national average. Despite this, recent surveys suggest that residents felt themselves to be in better health in comparison to the rest of London and England. This is indicative of the strong spirit of the area, with all of its diverse cultural and religious influences.

T2. Health and Wellbeing statistics for Lambeth, London and England

Reported Health Status	Lambeth	London	England
Good Health	71.6 %	70.8%	68.8%
Fairly Good Health	20.2%	20.9%	22.2%
Not Good Health	8.2%	8.3%	9.0%

The focus of this report

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

Culturally Sensitive Approach to Mental Health Support and Services

Southside Partnership

Southside Partnership exists to provide high quality services for adults with learning difficulties and mental health support needs. We are committed to supporting people to lead independent lives. At Southside we recognise that independence means different things to different people, whether it's making a cup of tea, choosing where to go on holiday, getting a job or moving to less supported accommodation.

Southside supports individuals to be as self-determined as possible. Southside aims to promote, encourage and empower all Service Users to achieve their individual and personal goals. We recognise that people need different types of support to make choices and decisions and we seek to support each individual to be ambitious about the level of independence they seek to achieve.

Our namesake, Franz Fanon's ideology of a culturally sensitive approach in relation to our work at Fanon with BME service users provides for a model of mental health provision that embraces emotional, cultural, social, educational and economic factors, which aims to ensure the freedom of the individual. Our approach to successfully delivering culturally sensitive support services within the resource centre model is:

- To empower and support service users to make informed decisions in relation to their lives.
- To offer internal 'taster' courses, activities and experiences aimed at building confidence,
- basic skills, which support the Recovery of Service Users to a level at which they are able to make their own choices to access external services, and aid social inclusion into their wider community.

- To develop strong partnerships with other agencies and services to improve their understanding and service delivery that meets our Service User's needs.
- To create 'revolving door' access to Fanon services that is used when needed.

This approach offers the Service User the flexibility and continual access to Fanon services, via the resource centre. It is more feasible to encourage Service Users that have been accessing mental health provision for a long period of time (more than five years) to reintegrate back into employment, family, career development training and relationships. Enabling them to increase or decrease the level of support that they feel is required at any given time.

Fanon House, the Tenancy Sustainment Team, Fanon Resource Centre, the FRC Women's Service, the Women's Hostel and the Training Flats are all examples of successfully delivered projects providing services and support to African and African Caribbean people experiencing mental ill health. Our culturally sensitive approach and person-centred support planning has enabled us to provide quality services, which have resulted in one service winning a BME award for excellence.

As we expand and develop our work the cultural background of Service Users will vary and this is recognised in our new project based in Merton, which works with African, African Caribbean and Asian service users. Although the work of Fanon Services has historically been focused on African and African Caribbean culture, we are able to share our expertise and understanding of discrimination and social exclusion based on skin colour, as well as work in partnership with other BME providers.

Scotch Bonnet Catering, our social enterprise, has expanded to include basic catering and hospitality training to Service Users as well as the external buffets and in-house provision. The Life and Work Skills Trainer has developed needs driven training programmes that are aimed at empowering and up-skilling Service Users to make independent and informed choices that improve their well being, economic status and social inclusion within their communities.

A Chart of Fanon Services

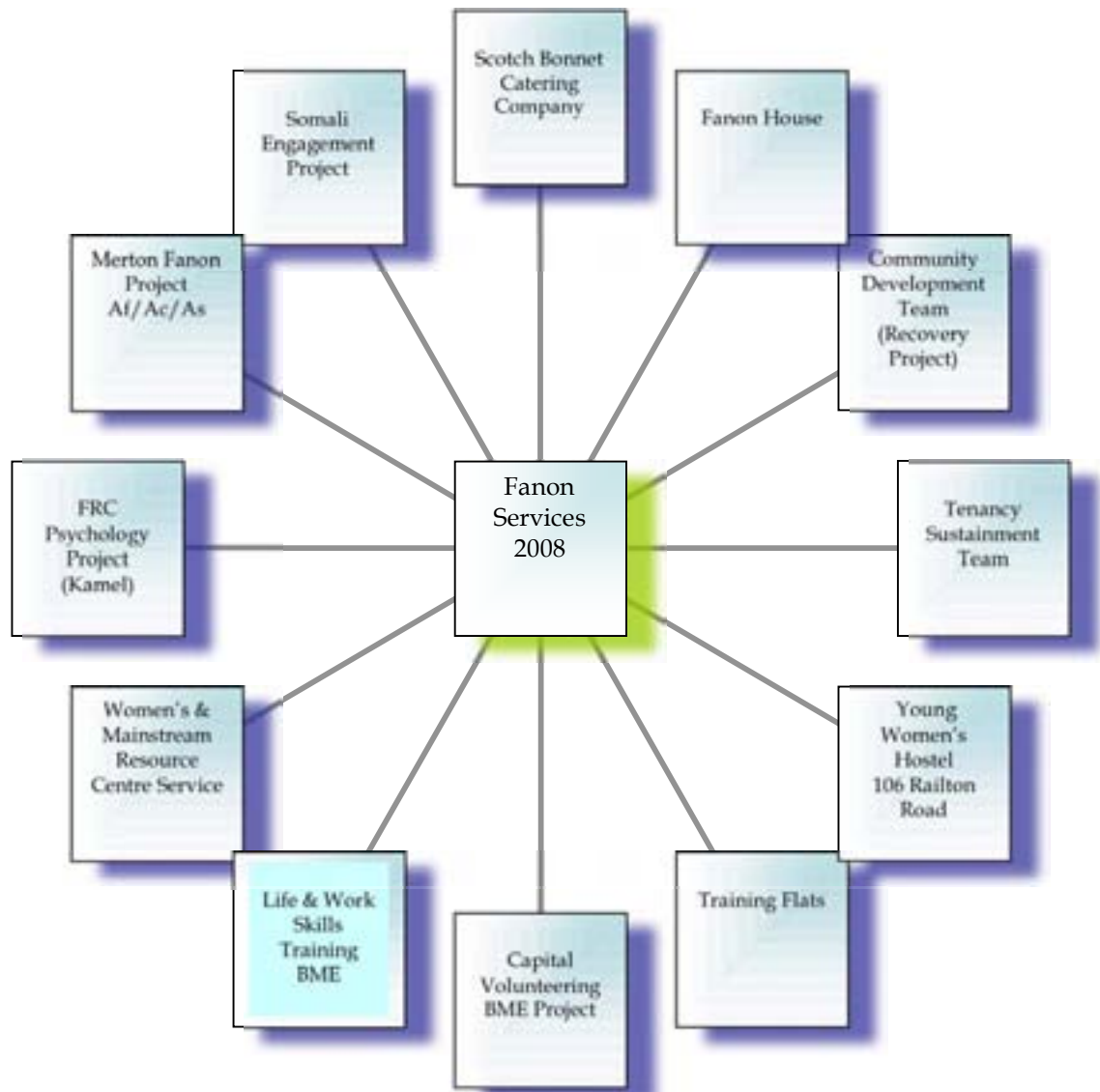


Figure 1

Methodology

The current debate and the vast literature available relating to mental health Recovery have been carefully reviewed by the initial project team. The Well-Being Project, sponsored by the California Department of Mental Health, was a landmark effort in which Service Users “*conducted a multifaceted study to define and explore factors promoting or deterring the well-being of persons diagnosed with serious mental illness*” Using quantitative survey research, focus groups, and oral histories, Campbell in 1993 arrived at a definition of Recovery that incorporated “good health, good food, and a decent place to live, all supported by an adequate income that is earned through meaningful work...”

A subsequent study conducted through semi structured interviews with consumers about Recovery, identified the most common factors associated with their success in dealing with a mental illness. Other researchers, also using semi structured interviews, suggested that the rediscovery and reconstruction of a sense of self were important to Recovery.

With this in mind we chose to mirror these approaches as this would yield the most effective and definitive exploration of the various perspectives of Recovery. We found that internal validity, as always, tended to be emphasised over external validity and as a result we wanted a more cross culturally valid approach. The Recovery project is borne out of this curiosity to explore the cross cultural validity of themes and assumptions that are present within the myriad of available Recovery literature.

Beyond the fascinating issues and themes which would emerge from the data would be the interactions and dynamics which manifest themselves within any discussions. Although these would be more difficult to convey in the report, we felt the project would provide the team with opportunities to explore Service User expectations and past experience of race, class and institutionalised racism and socio-economic issues which though this was difficult at times, has enriched the report.

We have outlined a step by step process of how the research was conducted:

Recruitment of Community Researchers

Five male BME service users were recruited as Community Researchers to work alongside the CDW and Community Research Co-ordinator for this project. The research provided an opportunity for service users to actively contribute their knowledge and experience to inform services.

The participants were recruited from community and mental health services through a series of consultations at various BME mental health services. Advertisements (see Appendix VIII) were distributed to BME services and organisations throughout Lambeth and Southwark to promote the research project and ensure full Service User engagement. Interested volunteers, offering to take on Community Researcher roles to support the project; were interviewed and provided with a briefing on the person specification and job descriptions (see Appendix VII). Our Equal Opportunities Policy was adhered to in all aspects of the recruitment process to ensure that candidates were treated fairly and equally.

Training and Support for Community Researchers

Training emphasised that Community Researchers should be impartial in their approach towards data collection. The following training was provided:

- UCLAN Training in mental health issues, Research, Data Collection & Analysis Techniques plus report writing and dissemination.
- Linked with the above training, researchers were offered the chance to study for one of 3 UCLan Certificates:
 - Certificate of Achievement in Community Research
 - University Certificate in Community Research
 - University Certificate Community Research and Mental Health
- Guilaine and Belonwu conducted training in facilitating Focus Groups & Motivational Interviewing Techniques
- Drug Awareness Training Workshop was provided by Lambeth Safeguarding Children. This enabled the researchers to get a sense of the effects of medication on respondents motivation and strategies for working with Service Users having 'dual diagnosis'

Support was provided by Service User Research Enterprise (SURE) to empower Service Users to carry out these activities sharing their knowledge, experience and expertise. Additional support was provided from both the CDW and the Community Research Coordinator in the development of personal skills.

Regular fortnightly meetings were held with the Research team and UCLan Support Worker. During these meetings relevant aspects of the Research were explored and discussed.

In addition, some members of the Research team attended a Social Perspectives Network/SCIE (Social Care Institute for Excellence) Mental Health Recovery day conference in London, October 2007. The Research team presented their project to the delegates and also ran a workshop exploring issues around caring. Attending this conference enabled the team to develop a wider perspective of mental health Recovery issues, and to learn about national perspectives and programmes, and how their project fitted into this framework.

The role of the Community Researchers

Initially, the 5 Community Researchers (Pel Essien, Lloyd Lindsey, Tim Hobbs, Milton Brown, and Alexei Weig) were trained by Belonwu Enzenma in Interview and Focus Group facilitation skills, and the process of community research. There were weekly team meetings, led by Guilaine Kinouani, and attended fortnightly by Joanna Hicks, who provided group guidance throughout the life of the project. In addition, UCLan workshops on community research were attended by all, led by Manjit Bola, and provided the opportunity to gain a certificate in the field. A number of Volunteers completed the work required, and achieved certificates respectively.

The interviews and questionnaires were formulated by Guilaine Kinouani in collaboration with the Community Researchers. Belonwu Enzenma left the project in July, followed by three of the Community Researchers. The remaining two Community Researchers (Lloyd Lindsey and Alexei Weig) applied for and were hired in the posts of Community Research Co-coordinators. Meetings and the reworking of interviews and questionnaires continued until October, when Merline Gabriel joined the project. Data collection

commenced at various Service User resource centres around the Lambeth area. This was followed by a period of analysis and discussion of the issues raised in the interviews.

During the analysis of the interviews, Lloyd Lindsey and Merline Gabriel left the project in November, and Guilaine Kinouani left in December. The project recommenced in February 2008 when Abdi Yussuf, a new Community Development Worker, joined Alexei Weig on the project and a process of re-uniting the data from the history of the project was commenced. In mid-February, four more CDW's joined the project (Elicia Mollineau-Angoy, Ian Wint, David Pinder and Pauline Etim-Ubah). Elicia Mollineau-Angoy led the project from that point on. The team began writing the report, re-analyzing the 22 interviews, incorporating the questionnaire analysis from NSUN, and organizing the launch event. Meetings continued with Joanna, who gave regular feedback and reviewed the team's work and the various drafts of the report.

Sample selection

The sampling methods used in this study are called Purposive and Snowball Sampling. Purposive sampling means identifying a particular group of people who meet the criteria and focus of a study. Snowball sampling means identifying prospective respondents and making contact with their friends and acquaintances. In the case of this study, African and African Caribbean male mental health Service Users aged between 18 to 65 years in Lambeth were selected and recruited from the services or places where they were more likely to be receiving services or socialising. The sample used in both the semi-structured interviews and the questionnaires was representative of the target respondents. It was also necessary to ensure that our links and contacts within the Fanon stable of services were utilised, in conjunction with the community contacts which the researchers brought to the project to ensure wide coverage of the Mental Health community. The numbers of respondents approached to engage with the research were 70 in total.

Ethics

The main ethical concerns identified were confidentiality and consent. Full ethical approval was obtained from UCLan which involved the completion of an Ethics Proforma (see Appendix I). Use of this template ensured identified areas of concern and additional areas including risk management, personal safety, data protection and storage were all given the necessary attention and approval.

The role of the Steering Group

The role of the Steering Group is to provide guidance and give constructive criticism to the Research team and to link the Research in with local strategic priorities. The initial plan was to link the community engagement project to the existing DRE Steering Group, but this was not successful as DRE Steering Group met irregularly during the course of the project. Further efforts were made yet again to develop a steering group specifically for the community engagement project, but this did not materialise due to the external commitments of group members. Instead, guidance and support were mainly provided by UCLan, with input from the Race Equality Lead, plus Denis O'Rourke, Assistant Director, Community Adult Mental Health, Lambeth PCT and Nicholas Campbell-Watts, Director Fanon

The involvement of local strategic planning and commissioning bodies

This research generated interest from the local commissioning bodies and support from the Community Adult Mental Health Team, Lambeth PCT and SLaM. Although unable to meet regularly as a steering group, they were accessible via email or telephone to share their experience and expertise where appropriate. Lambeth PCT also supported the application for further funding to increase the number of CDW's and Community Researchers to ensure the research was carried out to its fruition.

Accessing the targeted community

Respondents were recruited from community mental health settings. Consultations were held with staff and male Service Users from the following local BME services:

- **Afiya Trust:** the Trust is an important bridge between policy makers, service providers and BME communities as consumers of services.

- **Catch-A-Fiya:** Catch-A-Fiya is a survivor controlled forum for BME mental health system survivors, to facilitate positive change and support to personally development.
- **Share in Maudsley Black Action (African SIMBA):** Black mental health service user/survivor group aiming to provide a forum for mutual support and self-help, and to raise awareness of Black issues
- **Cares of Life Project - CoLP** is a community based model of care, which aims to improve the delivery of mental health care to Black people.
- **Fanon Resource Centre Lambeth:** the centre provides a service to African and African Caribbean people with mental health support needs in Lambeth.

Recovery Project team members first visited these sites and introduced themselves and the project to staff, before asking for permission to conduct interviews with some of the Service Users there. When this was granted, appointments were made with individual Service Users. Questionnaires were distributed to the above mentioned services and Service Users were encouraged to complete them, except in cases where literacy was a barrier, and staff members assisted. Further consultations were held with Service Users and staff from non BME Survivor/ Offender Groups and local statutory services to increase ownership and influence of the project in order to raise the profile of BME mental health issues and of the DRE agenda.

Research Tools Selected

This project is a combination of both qualitative and quantitative approaches and we adopted two processes of data collection to obtain the necessary information. The following tools were used:

- Semi-structured Individual interviews (see Appendix III)
- Questionnaires (see Appendix II)

A semi-structured interviewing technique was used as a qualitative data collection method where interviewers ask set questions. In total twenty-two, one to one interviews were carried out with each one lasting about one hour. This gave the interviewees the opportunity to express their own personal experiences or views in their own words. By using this method it gave an understanding of how people conceptualise Recovery and how they arrived at these sentiments, in a way that cannot be captured using quantitative methods. Although time consuming, this method was viewed as appropriate

as it allowed respondents to freely share their personal experiences. The 30 questionnaires were sent to Chandra Fowler at NSUN for analysis

Recording of Data Collection

A tape recorder was used with the consent of all participants in order to record all the information during the interviews. On the other hand, a large number of questionnaires were collected from the respondents in various community mental health organisations in the local area. In total 70 questionnaires were distributed to our target service users. Thirty questionnaires were completed and returned and responses were entered into a database without retaining any reference to which data belonged to which participant, so as to maintain anonymity and confidentiality.

Method of Data Analysis

A Thematic Analysis was used to analyse the data from the questionnaires along the basis of emerging themes by NSUN and the project team. The audio-tapes from the interviews were transcribed externally, owing to lack of capacity and time within the team, by OUTSEC. OUTSEC Limited provides an outsourced typing service for individuals and companies needing transcription of dictated sound files. Statistical Package for Social Sciences (SPSS) statistical package was also used to analyse the quantitative data.

Analysis & Findings

Despite the relatively small data set generated by the sample size, the one to one interviews contained a wealth of pertinent information and suggested a number of recurrent themes. Although some respondents had difficulties in understanding and responding to some questions, most displayed a significant degree of insight into their mental health and their interaction with mental health services. As noted previously, respondents were recruited through a number of local services, namely Catch-a-Fiya, African SIMBA, Cares of Life Project, and Fanon Resource Centre -Lambeth. All were men of African-Caribbean, African, or Mixed heritage, and had been receiving treatment for mental illness as inpatients in hospital, or in prison, at some point in their lives - some up to twenty years ago, others in the last few years.

Qualitative Analysis

Interviews

The transcribed interviews were analysed thematically by the research team as this proved the most effective means to bring out the qualitative richness of the data. They were analysed in relation to factors which impact upon recovery as addressed in the interviews: Barriers; Conceptualization and Facilitating Factors. A total of twenty-two (22) interview scripts were read by two people to ensure inter-rater reliability or concordance of the transcript's contents. The dominant themes that emerged are discussed below. Several underlying themes also emerged during the analysis of these interview scripts and are incorporated as separate sub-headings within our findings.

Barriers to Recovery

The stigma of being labelled mentally ill

"I have experienced hell in terms of being a person who is recognised as being mentally ill"

"Surviving, yes, but it is a different kind of survival. Something you take for granted is not for me because now I have been given this label, this is a new lifestyle ...When I became ill I felt as if I had committed a crime, the hospital I had gone to, I had never been to one, I was not prepared for it to be like a prison and I thought to myself, what have I done to arrive here? It felt like prison. It felt like orders, all those sensations, all those images I had."

Stigma and labelling from society emerged as a common barrier to recovery amongst 36% of the respondents, with 14% of the respondents saying that racism and discrimination were also barriers. This specifically related to media perceptions and the portrayal of individuals suffering with mental illness, public ignorance and general negative attitudes.

One participant said that other people's views, that he would become mentally unwell some day had become like a "self-fulfilling prophecy."

"I will not recover while people class it as a mental illness"

"We are still feared because as far as lot of people understand, you are in a funny farm and you are going to be locked up forever and ever and no one is going to help you"

The 'labels' given by society and diagnoses from medical professionals become definitions of who they are and what they will be in the future.

"Society stigmatizes people and if they see someone with that mental illness condition I do not think they are so willing, so accepting, and that is how I picked up on that prejudice or became affected by that prejudice and I either became withdrawn or segregated myself and realised that I became marginalised."

This has a negative impact on self-esteem as participants want to be seen as a whole person not just their mental health issues. One respondent said that in order to manage a mental health condition it was important not to let it define him as a person and added:

"...let it be a part of what happens and a part of my life rather than my whole life"

Lack of Familial Support and Personal Relationships

This negativity exists in a cyclic link with personal relationships. Many respondents viewed a breakdown in personal and family relationships as contributing to the lack of support required to sustain them on the road of recovery. This took the form of loneliness and isolation (32%), negativity from family and friends (14%), and many other experiences of social and family problems.

"My family life was terrible. It was really terrible. I therefore had to leave the family mentally and seek comfort, help and advice outside the family"

Many were disowned by their families at the onset or during their periods of crisis and have also grappled with being socially excluded. Social exclusion, rejection, a lack of family ties and support have left many respondents with very little motivation or enthusiasm to recover.

Medication

"Mentally ill or mad, and what that meant. And that was very peculiar, because now I would go down the street or be invited to a party and I would have this medication inside of me and things would not appear normal any longer, they were always affected, and so it was all slightly surreal, and I was being told this would be pretty much the accepted way of life, this is meant to be my new life, this ... the fact that I would be drugged up, and would keep walking around like this and slightly drooling and stiffness in joints is part of ... that is the cure, that is how someone in their 20s or 40s or 60s is acceptable to be the rest of their life. You see them on the street every day and you see they have got a problem and you know they are not ... they cannot be experiencing life, a proper life or a full life because they are so full of drugs they cannot. They cannot be really partaking in life because they are struggling; they have got so much medication inside them. So that was a struggle."

According to 27% of the respondents, medication helped their Recovery, in many cases simply saying that this was what Mental Health Professionals had said would help their recoveries. This was in contrast to the 9% of interviewees who viewed medication as a barrier to their process of Recovery. The medication, as one respondent stated, *“treats the symptoms and not the causes”* of his condition. He viewed this as being only a short-term solution. The prescription of anti-psychotics and anti-depressants were viewed as a ‘one size fit all’ approach to treatment which *“puts you in a box.”* The side effects of the prescribed drugs were seen as debilitating: *“Antipsychotic [drugs] makes me... I used [to] shake like this and the saliva used to come out of my mouth, very strong antipsychotic.”*

Additionally, diagnosis or misdiagnosis emerged as an accompanying issue to medication. A few participants believed that they were wrongly diagnosed and should not have been admitted to hospital.

“They done an assessment on me...they asked questions,[but] they never said they was questions, they put statements as said which was not true, right. They asked me questions like how I was brought up and I had no problems about it, then they asked me questions of ‘do you hear voices?’ that was a question put to me. And I must have laughed, I didn’t understand where he was coming from with that question, so yeah, I heard voices meaning the voices of I’m in prison, people playing music every day, people talking, but what I didn’t know what they took that [to mean]..Apparently they diagnosed paranoid schizophrenia. But also I have been here over 6 months and there have not been any symptoms reported”

A few participants stated that diagnosis was being used as a control mechanism that would keep people out of prison, but place them in the hospitals instead and also in cases where they may exhibit extreme behaviour:

“Yeah, they [the Mental Health team] thought there was something wrong with me. There is nothing wrong with me. They say there is something wrong with me but they don’t really know me. You know what I mean they are just diagnosing to keep me out of prison. Like if I was in prison I would have been out already.”

“I only took the medication...because they sectioned me and if I didn’t take it they would force it on me...even though it was very effective [if] you know what I mean, its just making me worse. I explained to them what was going on in my life then, and then they decided on this [diagnosis of] schizophrenia when they should have just dealt with the crime what they arrested me for.”

Environment

Local atmosphere was also viewed as a barrier to Recovery. Respondents stated that poor areas and homelessness (14%) hamper the recovery process and contributes to the 'revolving door' phenomenon. For 14% of respondents, drug and alcohol use has inhibited their Recovery. For example: unsupportive environments coupled with an active drug scene can be a cause of relapse.

"Recovery cannot occur when you are placed in the same old environment, with the same old habits, the same issues and the same people."

"It does not help to go back to an environment which...initially you need a fresh start and a fresh approach"

Conceptualisations of Recovery

“Getting back to a place where you were before you were ever ill”

There was general harmony amongst 45% of participants in terms of this concept of Recovery. These respondents described their idea of recovery with statements similar to the above quotation. Some referred to it as ‘getting back to a normal state of mind,’ others as ‘regaining past potential.’

Many participants (32%) viewed functionality, contributing to society and *“having a purpose”* as being indicative of recovery. This was in relation to employment and social factors. Many wanted to find work and to feel that they were advancing in that respect. Others felt that raising a stable family would come from their recovery. Many of the respondents expressed an interest in taking up employment and education which would enable them to give back to their communities and meaningfully contribute to society again: *“I’m alright now, let’s see who else I can bring up.”*

“I was thinking if people who’ve been through the system and are now survivors ... could somehow mentor people in the system. Now if I developed a service like that and it continued to grow and after I’d gone and left this world and it continued to be used and it was successful that would be...achievement for me.”

Twenty-three per cent (23%) of respondents felt that being able to *“move on”* and/or work towards a goal would be indications of Recovery. This was also linked to jobs and careers, as well as more personal aspirations, such as returning to their homeland or driving a car.

Others used analogies to expand on their ideas, such as the ‘AA roadside repair’ analogy, which 14% used:

“Recovery means coming out of this, it means, like when a car breaks down and you repair it...when you’re on the road and you break down and somebody comes and picks you up from there, like the AA or someone, that’s recovery”

Feeling comfortable and enjoying life was one of a few other concepts of Recovery, which also included happiness, not having to take medication again, and independence.

Many respondents believed that Recovery also entails developing confidence, a sense of self-worth, being treated equally, and the ability to stay in control and manage one's well-being.

Facilitating Factors

Family and Support Networks

“The most important steps to take to recover? Doing things, keeping busy with things that I enjoy to do. Medication, would help a hell of a lot. Really those things, I mean, keeping happy people around me. Keeping people happy, no keeping happy people not keeping people happy, keeping happy people around me because when people are happy you feel the vibe, anyway, those sorts of things that help speed up recovery.”

Family and having a support network is seen by 36% of participants as the main facilitating factor. The care and support of loved ones is significant to Recovery as respondents believe that having a safety net and knowing that someone is there to help them through the difficult times is extremely important. It generated hope and optimism for the future with 27% of participants wanting to start their own families. Furthermore, simply socialising and having a good time in good company was said by 18% of respondents to help Recovery. They said that it brings back a sense of confidence and being ‘normal’.

“What I strive for would be in the ideal world anyway, just a happily married family man with a wife and family and happy and my wife and kids are happy, I’m happy.”

Exercise & Leisure

Sport, exercise and physical health were seen by a significant proportion of participants (41%) as contributing to their recovery, with 9% saying that eating healthily also helps. Physical activity is a source of fun and good times, and helps to break out of a sense of isolation. Furthermore, playing for a team can help to make new friends, or strengthen old bonds.

“I used to have a lot of different muscles and stuff like that and it also keeps a healthy mind when you do what you do you know so, I would say good diet and exercise but not exercise that you don’t enjoy. Find something that you can enjoy and at the same time you’re keeping fit.”

Another facilitating factor for 27% of the respondents was developing a routine and “*keeping busy.*” This included attending local community organisations, exercise, reading, cooking, and other leisure activities.

A large amount of data was gathered in relation to the views of participants that a positive mentality and self awareness are extremely important factors on the path of Recovery from mental health issues. Optimism and positivity were seen by 32% to be highly important ingredients for a good Recovery. Further aspects along these lines included: having ambitions and aspirations; being or staying focused; having hope; self-esteem; and self-reflection. This shows that just as important as support from others, is support from within and being able to ‘help oneself.’

Employment

“Personally, I’d like to see myself trying to choose or making some first steps towards a career path”

Employment (23%) and Education (23%) are viewed by respondents as important facilitating factors in recovery. The idea of being ‘normal’ by having a job or attaining further qualifications to enter the world of work is a stabilising force for many service users. It helps in staying focused and positive, and provides a sense of direction. Many participants set these as goals and future aspirations as they provide an opportunity to regain control over their lives and “*move forward.*”

Faith & Spirituality

“Strength I think it comes from upbringing in a sense of, I heard somebody say something one day [about] how they deal with it, how they cope with it and what they want from it, depends on how they were brought up and I thought about that, what I had and I thought about my upbringing and I think to myself, well maybe I never was brought up so harshly and so you know in a Christian way and so much of the Bible. Was told stories and teaching morals and stuff like that then maybe I mean I don’t know but maybe I would not have got through this because it was, when you go through your hard times, when you lean back onto what you know or you look for some sort of support I mean I don’t think I’m explaining this properly but I mean my strength comes from that. My strength comes from the Bible. My strength comes from my mother because they’re old and they’re African and they’re old school...”

Twenty-seven percent (27%) of the respondents spoke of religion and spirituality as having a very positive impact on their pathway to recovery. The knowledge that there is a higher power within the universe and having a strong sense of faith were sources of comfort and support for many during periods of crisis. These respondents also believed that their faith in God helps them to survive and will continue to sustain them on their journey to recovery.

Medication

Medication was viewed by 27% of respondents to be a facilitating factor in their recovery because it helped to decrease the negative symptoms of their mental conditions. Despite this, several interviewees expressed that alternative treatments should be offered and one participant shared his experience of psychological therapy:

“Well to have a community team like a psychologist or anything like that to be on hand, then I can come to them anytime I need to talk or share my fears then they’ve got me on 24 hour report”

A few participants believed that if there were better understanding by psychiatrists of the ethnic backgrounds of service users, there would be less confusion and better communication, resulting in less misdiagnosis, as culture would be taken in to consideration during assessments.

“Now what you find with the psychiatrists, especially white psychiatrists,, they don’t understand ethnic majority backgrounds, so when they are talking about certain things, they take it in perception of ‘that’s peculiar’ because they don’t understand, it’s not I’m peculiar, it’s just that people live differently, different ways of living...if you look around here you see the majority of people in this unit are black, we have 2 white guys on this unit and 1 is white but got maybe Turkish or some other race in him, that makes 3, so you’ve got people who study from text books and believes everything what’s in black and white and these are the kind of people you are dealing with...”

Interestingly, one participant viewed marijuana as having a positive impact on his every day sense of wellbeing: *“What gives me confidence keeps me happy, is that due to the fact that I smoke marijuana...I am able to keep with in touch with reality.”*

Causal and Contributory Factors of Mental Illness

Many respondents shared their thoughts on their pathways into the mental health system and what they identified to be some of the causal factors. These contributory factors are a combination of social, financial and even coercive.

“So they gave me some forms, as I remember, and I thought well look, maybe if I make a commotion where I am, they will have to do something, they will sort something out for you. And so I made out I was having a fit, I sort of threw myself on the ground... instead of getting the kind of response I was hoping for or even an ambulance, they called the police...”

For many, every day stresses and problems, such as money, relationships etc., were seen as leading to their mental health condition. For others, a violent upbringing was said to be a major factor leading to their mental health condition. For others, causes included media perceptions, previous minor depression, hearing voices and being mentally *“unable to switch off.”*

Several respondents stated that their local environments led them to become involved in the use of illicit drugs, alcohol and substance misuse which they saw as contributing to their mental health condition. Unemployment or in some cases restricted finances caused many to source other avenues to support their drug habit. For many participants this led to criminal activity which resulted in contact with the criminal justice system and then into the mental health system or vice versa.

“I just got in trouble with the police, I was smoking drugs and things like that and because they didn’t understand me they asked me to see a doctor and that’s when they diagnosed me, but they didn’t know me. I was a total stranger and because they didn’t understand me or the way I was thinking or how I operate or I did my things they just decided that I had schizophrenia. So that means that someone could just come into the country from say Egypt, like my brother is from Egypt, and then sit there and when you talk to him... if you don’t understand the way he lives life, that is how they diagnosed me for schizophrenia when they don’t even know me”.

Of these participants, there was a lack of early intervention in most cases, which led to them being arrested, involuntarily sectioned and hospitalised.

“One of the benefits that I get on my money and that, they didn’t mail me so I ended up smashing up my flat, ending up in prison and they sent me to hospital, I wasn’t unwell I was upset...,I was angry that at the time I needed the money to furnish the rest of my flat ...I just go off to prison and go off to hospital.”

“Well I have been in there [prison] about six or seven times. When I was smashing my flat up I thought they would send me back over there because I recently got discharged from there but they didn’t sort my benefits out so I ended up coming back but this time I was in a medium secure unit.”

Additionally, some respondents expressed that a breakdown in their home, family structure and growing up with no one to provide much needed guidance, support and advice led to many poor choices and decisions. *“Not being taught how to juggle different things in their space”* The lack of a positive, male black role model and an opportunity to feel “listened to” caused many to seek acceptance from outside the family unit.

“Actually listening to me as an individual and stop assuming things, yeah, I suppose that would have probably helped a lot.”

While most people were positive about the idea of Recovery, there were some who were not hopeful about recovering as they felt stuck in their situation or not able to achieve their aspirations.

The majority of the participants we interviewed and those who completed questionnaires have been using the mental health service for more than 5 years with a significant number of the respondents being in the mental health service for 10 years or more.

One of the ways of managing or coping was seen as accepting and understanding or their mental health illness by the some of the respondents, while others were keen to discover their own ways and new ways of coping with their illness.

Table of Qualitative Findings: A Condensed Guide to Recovery

The following table is a summary of the ideas and experiences from participants' journeys of Recovery which they expressed during the interviews. This table shows the general connections between the different aspects of their individual recoveries. It is hoped that it could be used as a 'Condensed Guide to Recovery' for Service Users, Carers, and Mental Health Professionals, at least within this particular community. As this is not a well-known way of presenting qualitative data, a key to using this table is presented below:

Key to the following table

- The first thing that one might notice is that the heading of each column refers to a different aspect of Recovery in general, for example: 'What didn't help?', 'What did help?' etc.;
- Then, all of the ideas listed down the columns have been grouped into categories as one looks down the table. These have been given titles spanning all the way across the table, for example 'Relationships,' 'Religion/Spirituality,' etc.;
- Within these categories, all of the various ideas have been placed next to, or at least close to, other ideas which relate to them or are similar in nature. For example, 'Negative outlook,' in the Barriers column, has been placed next to 'Positive outlook' in the Facilitating Factors column. These two statements may have come from two different participants, and this is true of every other pair of ideas in the table. Therefore, **this table could be seen as a kind of 'imaginary conversation' about Recovery, taking place between all the various Service Users who took part in the interviews.**

PLEASE NOTE THE FOLLOWING

- Please remember that this particular arrangement and grouping, of the ideas and experiences from the interviews, is not meant to be definitive. There are different arrangements that could have been used to show different connections. However, **it is hoped that this table will make it easier for the reader to see general correlations in these findings, and even possible further suggestions about improving Male African and African Caribbean Service Users' experiences of Recovery in Lambeth.**
- Due to the methods necessary to create this table, the ideas and experiences are not, on the whole, arranged in order of popularity among participants. However, **the number of participants who shared a particular idea or experience is indicated in brackets within each box.**
- PLEASE NOTE: For those readers looking for a percentage breakdown of Recovery experiences and ideas, please refer to the table entitled "**Highest Qualitative Data Percentages**" (see Appendix IV)

Please refer to Table 3 on Pages 55 62

Qualitative Findings - Key Concepts of Recovery

T. 3 Qualitative Findings - Key Concepts of Recovery

Barriers: What didn't help?	Facilitative Factors: What did help?	Conceptualizations : What is Recovery?	Causal Factors: What caused the problems?	Other themes:
S E L F A W A R E N E S S / M E N T A L I T Y				
Confusion (1)	Keeping the mind active (1)	Getting back to a normal state of mind– (Getting back to the place where you were originally/Regain past potential) (6)		
Lack of focus (2)	Being or staying focused (4)	Ability to give your best performance (1)		
Memory loss (1)	Feedback on progress (1)	Getting your head (1)		
Suppressing own emotions/ anger (1)	Anger management (1)			
	Self awareness (1)	Self awareness (1)		
	Self reflection/ self analysis (2)	Being your self again (1)		
	Insight into own condition (2)	Ability to self reflect (1)		
Negative outlook (1)	Positive outlook (1)	Positive outlook (1)	Had minor depression before	
		Happiness (3)		
		Having something to look forward to (2)		

Barriers: What didn't help?	Facilitative Factors: What did help?	Conceptualizations : What is Recovery?	Causal Factors: What caused the problems?	Other themes:
Lack of confidence (1)	Optimism/ positivity (6)	Confidence (1)		
Lack of belief (1)	Self esteem/ self believe (3)	Taking up challenges (1)		
Lack of motivation (1)	Structured activities/ keeping busy (6)	Recovery is to do with an ambition (1)		
Inability to cope (1)	Resilience (3)	Ability to do the basics (1)	Not being able to juggle things	
	Self help (2)			
	Stability (1)	Control (1)		
		Stability (1)		
Inability to move forward (1)	Ambition/ future aspiration/ goals (5)	Being able to move on/ working towards a goal/ moving forward (4)		
	Plan of action (2)	Being able to do anything you want to do (1)		
	Acceptance and finding your own way (1)	Varied mental status (1)		
	Perseverance (1)	Progression (1)		
	Taking things one at a time (1)	Obtaining goals (1)		
		Being successful (1)		

Self fulfilling prophecy (1)	Hope (3)	Realistic (1)	Voices	
	Being able to listen or take advice (1)	Getting better (3)		
R E L A T I O N S H I P S				
Barriers: What didn't help?	Facilitative Factors: What did help?	Conceptualizations : What is Recovery?	Causal Factors: What caused the problems?	Other themes:
Family problems/ family separation (2)	Contact with family (not for support only) (2)		No family connection (left home early)	
Unstable family life (1)	Relationships/ Family life (with children) (6)			
Negativity (family & friends) (3)				
Relationship breakdown (1)	Socializing/ Having good friends (3)			
Vulnerability (1)	Love (1)			
Physical abuse (1)	Positive people (1)		Violent up bringing	
Rejection (1)	Someone to talk to (1)			
Inability to socialize (1)	Encouragement (1)			
Lack of support (3)	Support network - (e.g. from family, friends etc) (8)	Assistance from support services - 'like AA auto repair' (3)		
Lack of culture (1)	Awareness of one's culture			Traditional values

	(the individual) (1)			(not defined by one's mental illness)
Isolation (2)				
Loneliness (2)				
No sense of belonging (1)				
P H Y S I C A L W E L L B E I N G				
Barriers: What didn't help?	Facilitative Factors: What did help?	Conceptualizations : What is Recovery?	Causal Factors: What caused the problems?	Other themes:
Drug and alcohol use (3)	Avoiding substance misuse (1)		Substance misuse	
Overweight (1)	Sport/ Exercise (8)			
	Health/ fitness (1)			
Poor diet (2)	Healthy diet (2)			
	Personal hygiene (1)			
S T I G M A / D I S C R I M I N A T I O N				
Perception of inequality (1)	Communicating at the same level (1)	Respect from people (1)		Equality of man
Stigma/ labeling / society perception (8)	Not being labeled (1)	Public acceptance (mental illness) (1)		Stigma within religious groups
Racism/ Discrimination (3)	To be understood by peers (1)	Egalitarian (equal) approach to people (1)		Similarity in pathway to recovery in all

				racism
Barriers: What didn't help?	Facilitative Factors: What did help?	Conceptualizations : What is Recovery?	Causal Factors: What caused the problems?	Other themes:
				Needs transcend race and gender
Media perceptions (2)			Media perception	Concept of MH: everyone who got mental capacity will have a mental health challenge or issue at one point

R E L I G I O N / S P I R I T U A L I T Y

Barriers: What didn't help?	Facilitative Factors: What did help?	Conceptualizations : What is Recovery?	Causal Factors: What caused the problems?	Other themes:
	Spirituality/ God's support (6)	Forgiveness from God (1)		
	Meditation (1)			
	Sense of morality (1)			

M E N T A L H E A L T H S E R V I C E S

Barriers: What didn't help?	Facilitative Factors: What did help?	Conceptualizations : What is Recovery?	Causal Factors: What caused the problems?	Other themes:
Professionals' lack of understanding (2)	Contact with professionals (1)			Misdiagnosis: own MH perception different from doctor's diagnosis
Lack of cultural awareness from professionals (1)	Culturally specific services (2)			
No recognition of cultural differences (for professionals) (1)	Talking therapies (e.g. counseling) (1)			
Not dealing with people as individuals (for professional) (1)	Contact with CPN (1)			
Lack of freedom (hospital leave) (1)	Independence (4)	Independence (2)		
Hospitalization – Negative hospital environment (1)	Understanding one's rights in the hospital (1)			
Sectioning & hospitalization (1)	Hospital (1)			
Unfriendly (hospital) staff (1)				
Barriers – What didn't help?	Facilitative Factors – What did help?	Conceptualizations – What is Recovery?	Causal Factors –	Other themes

			What caused the problems?	
Medication effect (2)	Medication (6)	not having to take medications again (2)		Concept of MH: chemical imbalance
Medication (non-compliance) (1)		Taking medications (1)		
E C O N O M I C / H O U S I N G / L E A R N I N G				
Financial problems (2)	Financial security (1)	Feeling comfortable/ enjoying life - (no worries including financial) (3)	Every day stresses/ problems (e.g. financial, economic and social)	
Unemployment (2)	Employment (5)	Ability to be responsible - (e.g. financial responsibility) (3)		
Homelessness (3)	Housing (2)			
Increased isolation by living in or moving to new area) (3)	New location (1)			
Immigration status (1)				
	Learning & education (5)			
S O C I A L A T M O S P H E R E				
Returning to the same setting (1)	Avoiding stressful situations/ triggers (2)			Triggers: Area of living, avoiding stressful situations
Criminal activity (1)	Contributing to society (2)	Functional/ contributing to society/ Having a	Prison	

		purpose(7)		
Drugs atmosphere (1)				
Barriers – What didn't help?	Facilitative Factors – What did help?	Conceptualizations – What is Recovery?	Causal Factors – What caused the problems?	Other themes
	Altruism (1)	Doing the right thing and keeping a level head (1)		
Mixing with the wrong people(1)	Positive Role models (1)	Shift in value systems (1)		
L E I S U R E / E N T E R T A I N M E N T				
	Relaxation (1)		Things in their space (unable to switch off)	
	Sleep/ rest (1)			
	Reading (1)			
	Art/ cooking (1)			
	Music (1)			
	Leisure & entertainment activities (1)			
	Marijuana (1)			

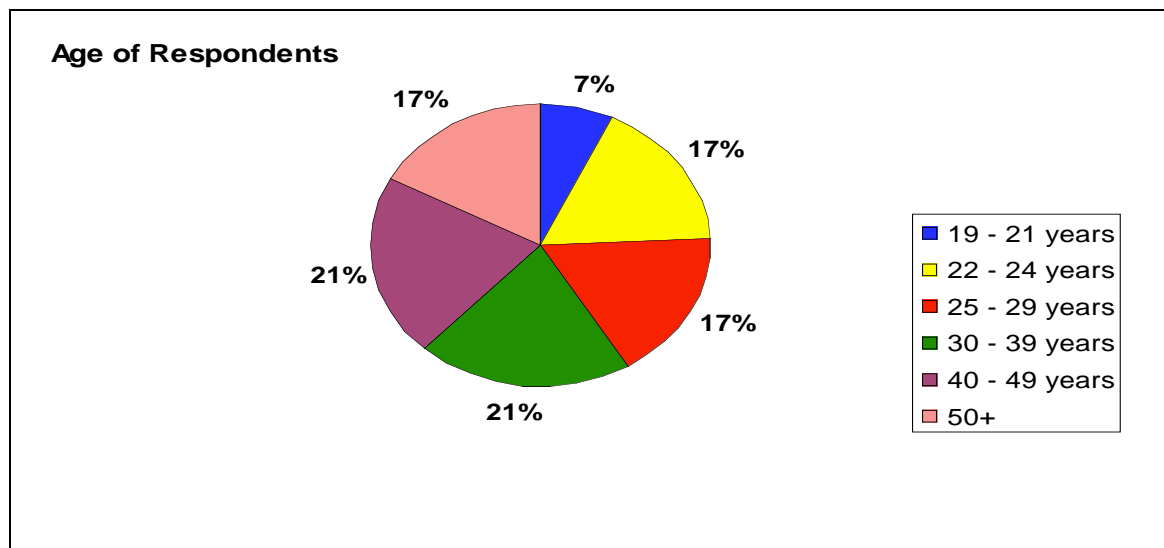
Quantitative Analysis

The quantitative data was collected using questionnaires with a total of seventy (70) being distributed to the target group, with thirty (30) being completed and returned.

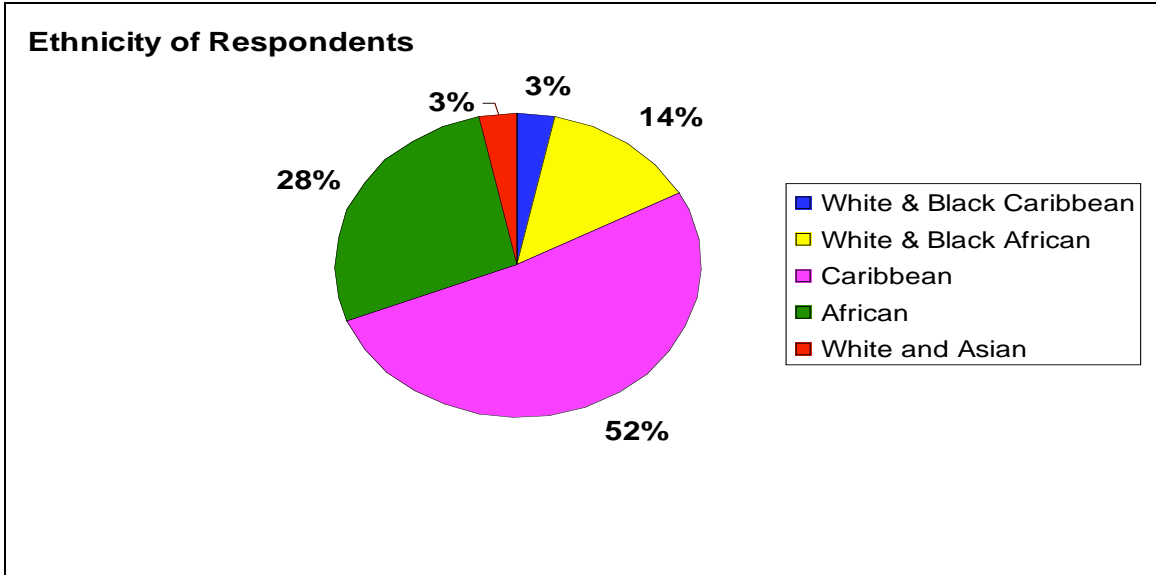
Demographic Characteristics

The first section of the questionnaire included a group of core questions (see Appendix II), which focused on demographic variables including: age, ethnicity, birthplace and citizenship, length of time in the UK, first language, religion, sexuality, disability and length of service use. The second half of the questionnaire focused on factors which referred directly to recovery. Respondents were asked to indicate on a five point ordinal scale ranging from 'I strongly disagree' to 'I strongly agree' the factors which positively influence their journey to recovery.

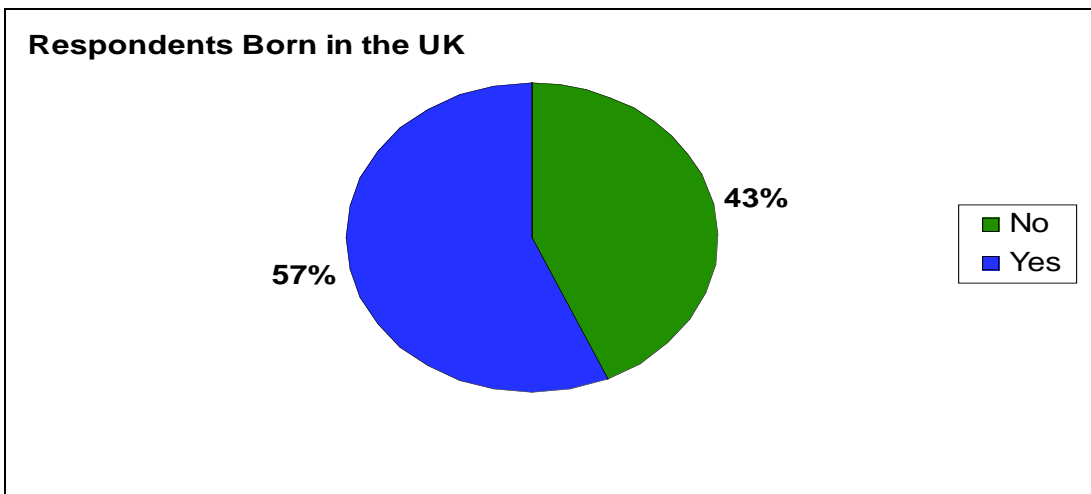
All participants were male due to the focus of the research and ranged in age from 19 to 50 years plus. The mean age for the whole sample (n=30) was 35.8

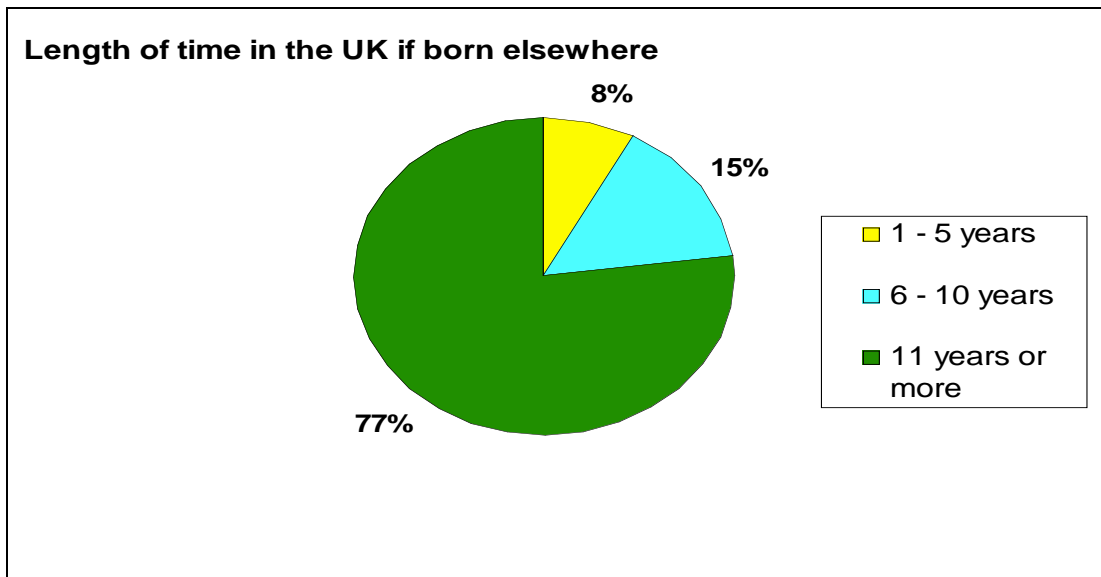
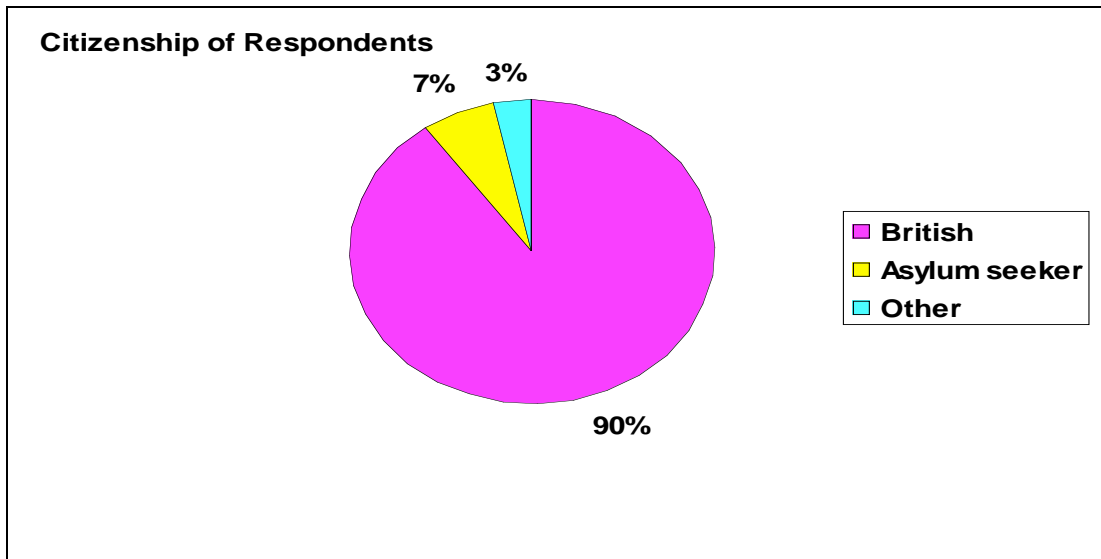


The ethnicity of participants comprised three major categories with 15 (50%) being Caribbean; 8 (26.7%) African, and 3 (13.3 %) being White and Black African.



The tables below describe where the respondents were born, their citizenship status and the length of time they have spent in the UK. Seventeen respondents (57%) were born in the UK with 27 (90%) of the whole sample having British citizenship. Asylum seekers accounted for 7% of the sample population, while 3% did not indicate their citizenship status. Thirteen respondents (43%) were born outside the UK, and of that number 10 (77%) lived in the country for eleven years or more. These were investigated for correlations to establish if there was any significance between this group and length of service use, which will be discussed later in our findings.





Despite a small data set there was a diverse range of languages spoken by our respondents. There were six languages spoken in total including English. Patois⁵ accounted for 6.7% while 3.3% of respondents each spoke Krio⁶, Shona⁷, Timini⁸, and Acholi⁹.

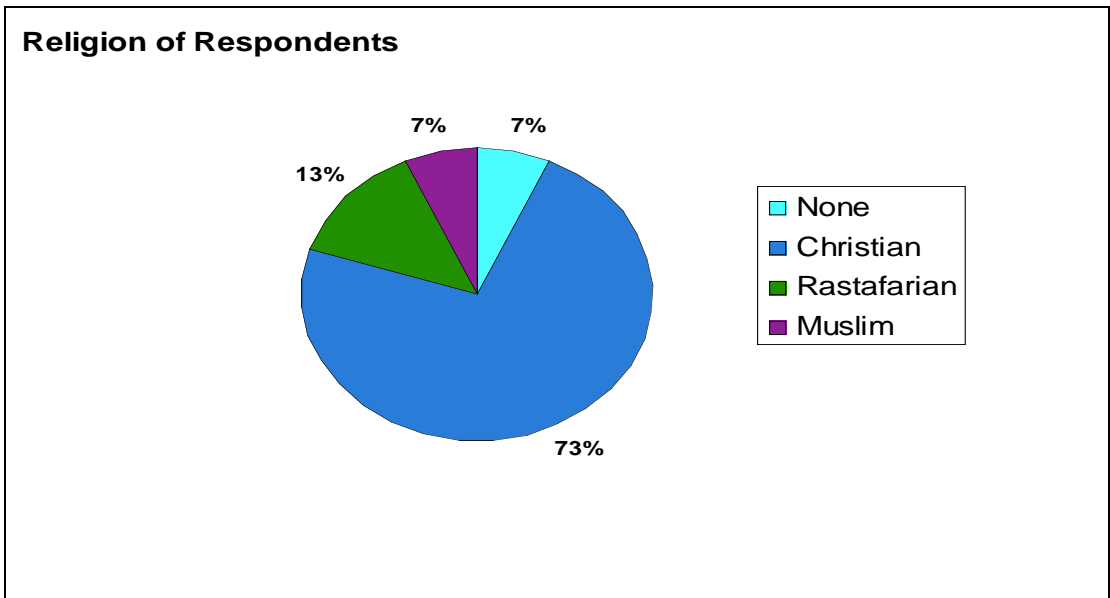
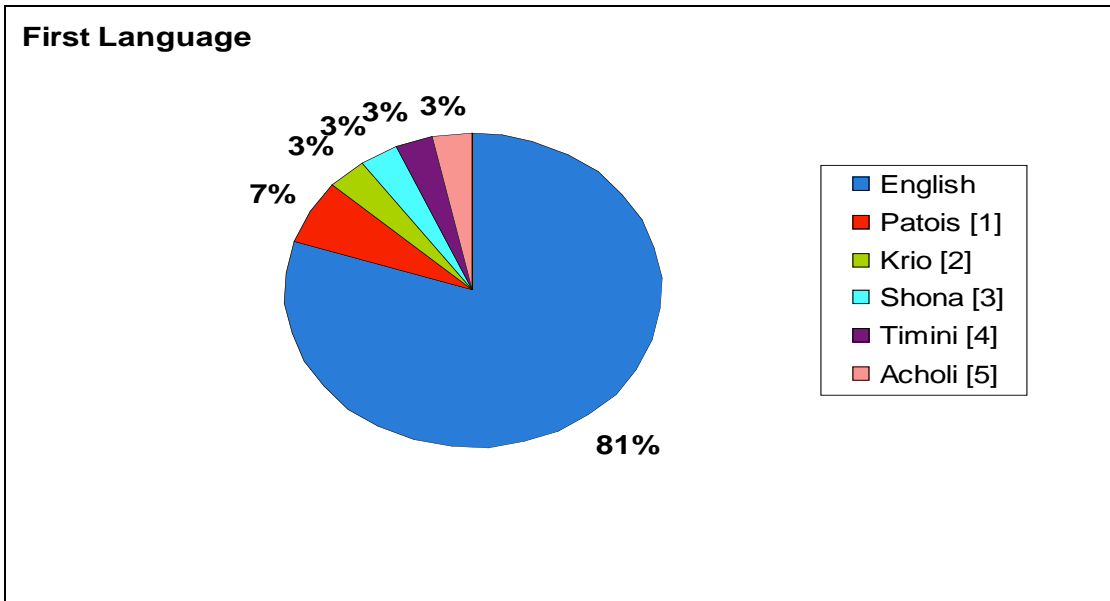
⁵ A language that has developed from a mixture of other languages = (Creole)

⁶ Krio is the language spoken in Sierra Leone which originated from a pidgin. A pidgin can become the first language of a region, when it is known as a 'creole'. Examples of creoles based on English are Gullah (South Carolina and Georgia in the United States), Tok Pisin (Papua New Guinea), and the creoles of the Caribbean region.

⁷ The national language of Zimbabwe

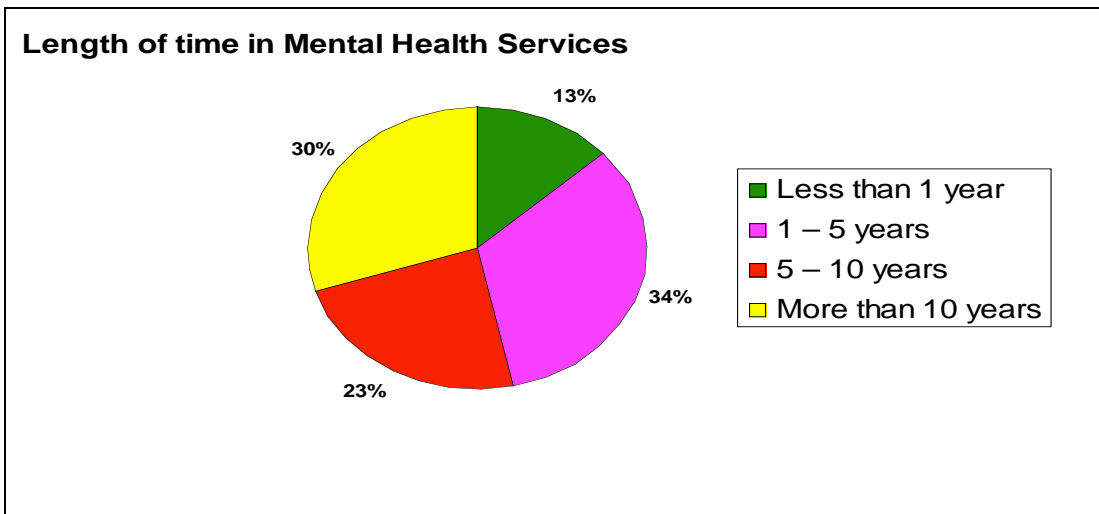
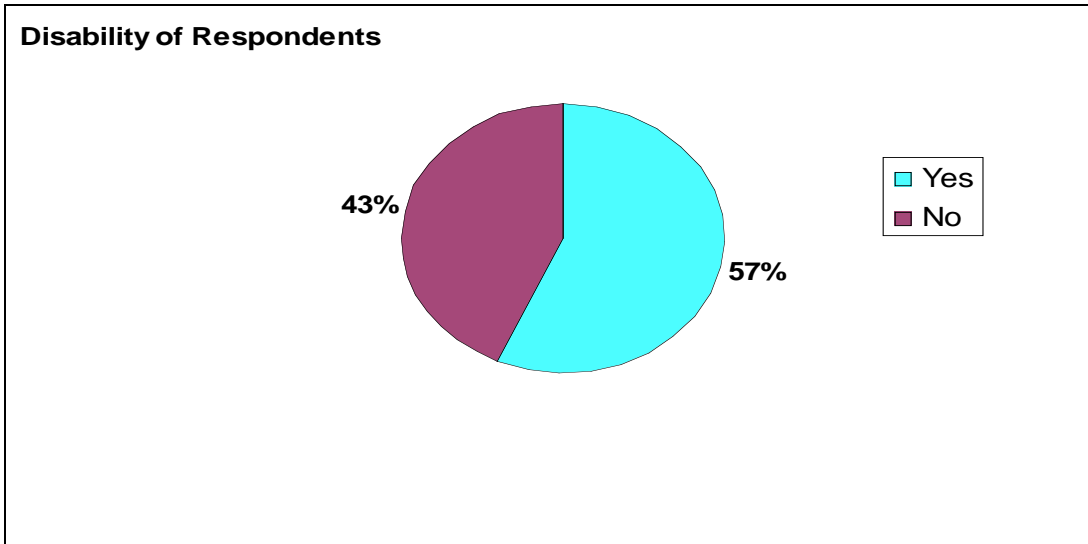
⁸ A form of dialect spoken in Sierra Leone

⁹ Acholi is the language primarily spoken by the Acholi people in the districts of Gulu, Kitgum and Pader, a region known as Acholiland in northern Uganda.



Seventy-three percent of the respondents identified Christianity as their religion. Rastafarianism was the second highest percentage with 13.3% of the participants and 6.7% identified with being Moslem and a further 6.7% did not respond to this question. Almost all respondents (86.7%) of the sample confirmed their sexuality as heterosexual with only 3.3% identified as homosexual and no response from one participant.

Fifty-six per cent of the sample population identified themselves as having a disability which included mental illness.



Service use length was the final core question and 34% of respondents indicated that they have been using mental health services between 1 and 5 years. However this was followed closely by 30% of participants who indicated that they have been using mental health services for more than ten years. Twenty-three percent have been engaged with services between 5 and 10 years and only 13% have been using services for less than one year.

Statistical Analysis

The statistical tests selected for analysing the data were the Chi-square Tests which included: Pearson's Chi-Square, Likelihood Ratio and Linear-by-Linear Association. These were purposely selected to explore possible correlations within the data - between the variables in the core questions and the ordinal categories.

The strongest correlations were found between whether people felt they were on the path to recovery and whether they had the support of their friends. This is substantiated by the qualitative data drawn from the interviews. (see Appendix IV) Support from family and friends were mentioned by nearly half of the respondents. Despite this possible link, the relationship was not statistically significant but may warrant future exploration with a larger sample. (Table 3)

T. 3 Cross-tabulation of Path to Recovery and Support from Friends

**I'm on the path to recovery and or maintaining my gains
* My friends support me**

		My friends support me		Total
		Yes	No	
I'm on the path to recovery and or maintaining my gains	I strongly agree	5	2	7
	I agree	7	1	8
	Neutral	0	0	0
	I disagree	1	4	5
	I strongly disagree	1		1
Total		14	7	21

From the table we can see that a total of 15 respondents out of 21 either agreed or strongly agreed that they were on the path to recovery and support from their friends is important to their recovery process.

Another possible relationship explored was between the length of time in the UK – for those born in another country – and the length of time accessing and using mental health services. Unfortunately, no significant correlations were found for this or between any of the other variables from the questionnaires. One possible explanation is due to the small sample size and the number of completed questionnaires returned. Future research in this area should take this into consideration.

T.4 Statistical Tests and Levels of Significance

Chi-Square Tests			
	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	7.034(a)	3	.071
Likelihood Ratio	7.325	3	.062
Linear-by-Linear Association	2.000	1	.157
N of Valid Cases	21		

a 7 cells (87.5%) have expected count less than 5. The minimum expected count is .33.

As shown in the table above, the acceptable the level of significance is $p < 0.05$. We can then confirm that the probability of any relationships within the data, when, (Pearson Chi-Square = .071, Likelihood Ratio = .062, Linear-by-Linear Association = .157) is too low for any significant correlations in a positive or negative direction.

The responses from the second half of the questionnaire which focused on the factors important to recovery were then ranked in order of importance. A total of 43 factors were placed in descending order of importance – with the most important at the beginning and the least important at the end (see Appendix V).

T.5 15 Most Important Factors to Recovery

1. Having a positive sense of personal identity outside my illness is important to my recovery
2. Having a sense of meaning in life is important to my recovery
3. Having my rights respected is important to my recovery
4. Having positive relationships is important to my recovery
5. Having a sense of control and feeling empowered is important to my recovery
6. Improving my general health and wellness is important to my recovery
7. Being involved in personally meaningful activities is important to my recovery
8. Having assistance in a crisis is important to my recovery
9. Having hope is important to my recovery
10. Identifying and building on personal strengths is important to my recovery
11. Having my basic needs met is important to my recovery
12. Support from friends is important to recovery
13. Taking on new challenges is important to my recovery
14. Having helpers who really care is important to my recovery
15. Being active in directing my own recovery is important to my recovery

The first 15 items complement the feedback received from the interviews and support the themes which emerged from the factors which facilitate recovery (see Appendix V). All other factors were all seen as equally important to the recovery process, as we have confirmed from our qualitative data. However they did not rank as highly within our quantitative data and will be discussed further in our limitations.

Discussion

It is necessary that we discuss the limitations of our research project, before any inferences can be drawn from the above results. This is the first piece of research undertaken in the UK with male service users within the BME community in relation to recovery and mental health. It is hoped that by discussing our limitations it will positively inform future researchers on study design and how to manage challenges.

Limitations

- Retention of the community researchers created some obstacles during the course of the project. Due to their voluntary status it proved difficult to encourage a more dedicated approach. A 'stipend' or incentive payment may have promoted a greater level of commitment from the group. This would have demonstrated recognition for the work they were doing.
- Sustainability of community volunteer researchers was another issue which impacted on the progress and timely completion of the project. They all moved on at the end of the data collection process. This left a gap for a period in the programme, a hiatus was created which impacted on the continuation and development of the programme in terms of the threads being 'passed on' as opposed to being 'picked up'
- Steering group sustainability: A much more formal or rigorous approach needed to have been used in managing this activity in order to ensure it took place at regular intervals. Possibly the task of organising it could have been delegated amongst the team. This would have enabled an external body to be involved in guiding the team, keep the Project on track and hold them accountable.
- Scope of the project - more than one CDW: Having only one CDW limited the amount of work that could be undertaken, as this project was only one aspect of the CDW role and there were other areas of work that needed the same level (if not more) of commitment.
- Scope of the project – no consultation process: A more robust consultation process was needed that engaged service users and other stakeholders in developing the terms of reference and scope of the project. This would have enabled a more valid output as well as better engagement at all stages of the Project to inform the various activities.
- Better utilisation of human resources: In general, it was felt by those working as community researchers that a more efficient use of the people working within the

project would have resulted in better delegation of duties. This created a lack of ownership and impacted on retention levels throughout the duration of the project as discussed earlier.

- Focus groups having not taken place: Their application to the tasks at hand by the project team is unquestionable. However, more efficient use of the available human resources would have enabled continued engagement with individual service users and service user groups so that this activity (Focus Groups) could take place with some form of regularity.
- Outsourcing data analysis (quantitative only): The data analysis was initially outsourced which then ran into logistical problems that could have impacted on the delivery of the project. It was perhaps unclear if the research objectives were communicated to the data analysts.
- Misunderstanding of dialects / accents: This data was also outsourced (qualitative), and it was found that quite a number of the interviews contained 'holes' in the transcription of the data due to misheard / unclear sound. This problem could have been addressed by using a more closely cultural transcription service that may, through having a sense of language use filled in the blanks. The return of data, themed analysis and broader data interpretation would also have been more easily facilitated with an organisation closer to home.
- Interview bias re: interview questions: All of the researchers had undergone some training in research methodology, interview techniques and focus group training and would have benefitted from having the opportunity to practice these skills before the roll out of the research.
- Difficulties experienced in obtaining quantitative data: due to the small number of interviews that were conducted and the low number of completed questionnaires returned, it was hard to draw out data that could be used to numerically demonstrate assertions made in the report.

- Number of questionnaires returned was less than half distributed: A better system of disseminating and collecting the questionnaires and emphasising the importance of them being completed could have helped provide sufficient data for more robust findings. It may have been useful to run questionnaire filling sessions with participants and centre staff in-situ.
- Too many questions in questionnaire for such a small sample: Overall the questionnaire needed to have been much more rigorously piloted and the instrument more 'user friendly' before being used as a survey tool. This would have enabled tighter and more fluid questions and richer data yield.

Despite our various limitations, we have found some very interesting and valuable information. The diversity within the demographics of Lambeth's BME community was wonderfully captured, despite having a small number of participants. It clearly reflects the need for more culturally appropriate training and services and within the borough.

Recommendations

The findings generally indicate that the focus of recommendations should be on prevention as opposed to cure and by looking at opportunities to address some of the bio-psycho-social issues we may go some way to understanding how to deliver practice that echoes this. Through cross-agency working and practical partnerships service users will be able to access a range of provisions that more closely serve their needs. This will need to take place in an environment where statutory and voluntary organisations are consistent in what they say about Mental Health and which reflects the objectives of the 'Delivering Race Equality agenda. The following recommendations arise directly from the project findings and take in to account the actions that need to be taken at the grassroots level – practitioners and service providers, strategic level – commissioners and policy makers and an illustration of the impact if they are followed through for service users.

1. Being able to contribute to society

Grass Roots

- Mental Health services should develop schemes that give service users some responsibilities (where appropriate) in the services they attend such as volunteering

Strategic

- Mental Health Services should work in partnerships with community organisations to provide voluntary opportunities to service users in their local area
- Training programmes should be developed to enable service providers to facilitate mentoring and volunteering programmes within their services

Impact

- Service users will improve their self esteem and gain experience that will support them in regaining their independence

- Service users will feel more empowered and give them some ownership of the services that they engage with.

2. Awareness of Mental Health in the Community

Grass Roots

- We recommend that a series of guides be produced that explain the terminology used and different ways of accessing mental health services to tackle the fear and lack of understanding within BME communities.
- The guides should be produced in an accessible and culturally specific format e.g. using diverse language, texts, emails, postcard/credit card size publications and e-newsletters.

Strategic

- Mental health professionals should work with community organisations to develop clear explanations of mental health terms and include what a diagnosis means, the symptoms likely to be experienced and also preventative methods that can be sought such as talking to friends and family
- Mental Health professionals should consult with community organisations and advocates to compile information about the sectioning procedure including why a person is likely to be sectioned, what being sectioned means, what will happen during a section and what a person's rights are while under a section

Impact

- People will feel more informed about mental health and more comfortable discussing their own mental health concerns without being put off by intimidating labels.
- People can be encouraged to recognise any problems earlier and be able to approach mental health services or seek support where needed.
- Increased clarity of the procedures within sectioning and an understanding of the efficacy of advocacy.

3. EARS (Empathy and Advice, Responsive Support)

Grass Roots

- Mental Health Services in Lambeth should set up or link into existing service user forums. Service users can voice their opinions and share their experiences of Recovery with others.
- Mental Health Services should develop more effective ways of communicating with service users, e.g. setting up suggestion boxes at resource centres/hospitals and regular meetings with service users.
- Services should recognise the importance of family and peer support in a service user's long term Recovery and develop mechanisms, such as self help groups, mentoring and befriending schemes, as a key facilitating factor of Recovery.

Strategic

- Mental Health Services should put the thoughts, feelings, experiences and ideas of service users at the centre of any Recovery strategy.
- Psychiatrists should make a commitment to attend both in-patient and outpatient service user forums to create an open dialogue between service users and the Mental Health professionals.
- Issues raised at service user forums should be fed back to Royal College of Psychiatrists, Registered Medical Officers and Senior Mental Health professionals.
- A Lambeth wide service user network should be facilitated to incorporating all service user forums. NSUN (National Survivors User Network) offer a good example of how this is done on a national level.
- There should be more emphasis on continuous access to talking therapies for service users and the building of one-to-one relationships from admission to discharge and upon referral to other services.

Impact

- The views of service users can be disseminated to statutory organisations to inform policy making in a meaningful and coordinated way.
- Psychiatrists will improve their cultural awareness and understanding of the experience of living with a mental health diagnosis.
- Service users will be able to learn from each other and share experiences and personal insight

4. Faith and Spirituality

Grass Roots

- Mental Health Services should use more faith-based organisations and their facilities for events and activities. A good example is the Lorrimore drop-in at St. Paul's church in Southwark.
- All Faith leaders should be encouraged to become advocates for BME service users. Appropriate training, taking into account spiritual beliefs, should be developed to facilitate this.
- Mental Health service providers should record the Faith or spiritual belief of all service users they engage with, if service users wish to disclose this information.

Strategic

- Lambeth CDW team should work in partnership with the Spirituality and Pastoral Care service at SLAM to further investigate the role faith can have in supporting BME service users in their Recovery.
- Good practice from Homerton Hospital's Department of Spirituality, Religious and Cultural Care should be disseminated as an example of how faith can be fully incorporated in a person's mental health care. They have a chaplaincy team which cover a diverse range of faiths, a Sanctuary and Shabbat room for quiet prayer and thought and regular religious services.
- Statutory organisations should investigate the role faith-based organisations can have in supporting BME service users in other aspects of their Recovery such as housing needs, social services and

education/training. A good example of this is St. Leonards Church in Lambeth that provide support on housing issues and work with homeless people in the community.

- Mental Health Services should work with Faith Leaders to develop a training programme for front line staff about the diverse spiritual beliefs within BME communities.

Impact

- Mental Health services will be able to engage with more BME communities in settings where they feel comfortable like churches and other places of worship.
- A clear understanding of the different spiritual beliefs held by BME communities in Lambeth will inform service delivery and ensure the faith needs of the BME service users are appropriately facilitated
- Spirituality and Faith will be embedded, where requested, in Recovery pathways and stakeholders will acknowledge the importance of spirituality and faith in a person's Recovery.

5. Cross Agency Working

Grass Roots

- Good practice across statutory agencies that engage with service users (e.g. Criminal Justice, Substance Misuse, Social Services, Housing and Benefits services) should be disseminated across services via existing channels.
- Frontline staff should make effective use of communication methods with other services including shared learning and networking opportunities, working groups and email bulletins

Strategic

- There needs to be an honest discussion into how to improve cross agency working with clear responsibilities for each agency on how to work together more effectively.

- Development of cross-agency wide toolkits and training packages

Impact

- Service users are treated holistically with all issues taken into account (bio-psycho-social approach) when assessing their mental health and supporting their Recovery
- More awareness and better understanding by service providers and statutory agencies of their various roles and functions.
- Adoption of a cohesive approach to supporting service users on their journey through Recovery.

6. Learning and Education

Grass Roots

- Service users should have the opportunity to develop new skills and should also evaluate any learning opportunities that they participate in.
- More accredited courses should be available at mental health services, similar to the NVQ and training programmes run at the Fanon Resource Centre Lambeth and the St. Giles Trust.

Strategic

- Mental Health Services should engage in robust partnerships with education and training providers to bring in, or create the expertise within Mental Health Services, to develop projects and models of working.
- The Return to Learning programme from Lambeth College should be disseminated as widely as possible as a good model for introducing service users back into education.
- Appropriate monitoring and evaluation should be carried out to capture the outcomes of these partnerships including the feedback from service users to inform future service delivery.

Impact

- Service users have a wider range of skills that will support them after their engagement with mental health services.

- More wide-spread participation in educational and training activities
- Service users will have increased confidence through a greater sense of achievement that will enhance their journey of Recovery.

7. Employment and Workability

Grass Roots

- Mental Health Services should actively participate in networks like the Lambeth Employers and Training Providers Network (LETP).
- Good practice about how to engage with BME mental health service users should be disseminated to local employment agencies and employers.
- Mental health professionals or advocates should be posted in Job Centre Plus offices in Lambeth to provide support to clients with mental health needs on a regular basis (at least once a month)
- Mental health services in partnership with employers should promote positive images of people with mental health issues and reduce the stigma around mental health issues in the work place

Strategic

- A 'champion' for workability within the Mental Health Service in Lambeth should liaise with the Lambeth PCT representative on the Lambeth Employment and Skills Board to inform the implementation of the Lambeth's Plan for Employment and Skills 2007-2012
- Mental Health services should work with employment gateway organisations like The Gain Project and Tomorrow's People to create more 'Therapeutic Job' opportunities that support BME service users to slowly integrate into work.
- Commissioners for Mental Health Services should fund services that include pathways to employment as part of the service offered to BME service users
- London Borough of Lambeth should allocate more resources to projects and community organisations so they can develop flexible workability

programmes that support BME service users into employment through an optional transition period.

- London Borough of Lambeth's Black and Asian Minorities Ethnic (BAME) Incapacity Benefit project should be disseminated and piloted in other community organisations
- Mental Health Awareness training programmes should be developed for Employers, Job Centre Plus and Benefits staff in Lambeth.
- A benchmark or standard should be developed for Employers who demonstrate good practice in employing and supporting service users and other people experiencing mental health issues in the workplace.

Impact

- BME services users would have support from staff across agencies and outside the Mental Health Services that have an increased awareness of their needs and can respond appropriately.
- BME service users that are the most vulnerable and hard to reach will be able to access more services based in their local community. These services will have increased depth of resources and facilities to work more effectively.
- Employers and employees are more aware of mental health issues and have the skills and knowledge to create an understanding and tolerant work environment
- Front line staff in Job Centre Plus and Benefit offices in Lambeth are able to support BME services users more effectively and signpost members of the BME community to Mental Health Services where appropriate.

8. Alternatives to Medication

Grass Roots

- Mental Health Service should collect monitoring on the number of participants that participate in regular leisure activities and what type of activities they do e.g. arts, sport, music or cooking etc.

Strategic

- A study in partnership with community organisations should be commissioned to look at the benefits leisure activities have on service users' Recovery
- Monitoring systems should be developed that can accurately capture both the 'softer' outcomes (such as improved confidence and a strong sense of self) of service users and 'self-reported' states of Recovery

Impact

- Better understanding into the role leisure activities have in facilitating Recovery
- Collection of a strong evidence base that could inform future commission strategies for Mental Health services encouraging more variety in services and the opportunity for rehabilitation in the community

9. Representation of BME Women in the Mental Health Services

Grass Roots

- A trend analysis into the experiences of women in the mental health services that would highlight the cause and effect of mental ill health and demonstrate potential pathways to Recovery.
- There should be further training for staff at women's' services so that the most vulnerable and hard to reach women are referred to mental health services as early as possible.

Strategic

- A longitudinal study should be carried out that looks at why BME women are over-represented in mental health services in Lambeth and what are the coping mechanisms or shielding factors in their lives that prevent them from accessing the mental health services.
- A cross-agency framework should be developed for referrals into the mental health service taking into account issues around confidentiality and service user's sensitivity regarding their mental health.

Impact

- A common referral procedure that leads to better monitoring and recording so we can gain a clear understanding of the people who access, or need to access, our service and help in developing services that met their needs.
- Data that highlights social variances which informs the development of preventative mental health strategies that are transferable across BME communities.

It is our hope that these recommendations will be the beginning of a process of reform not just in the delivery of mental health services, but also in the commissioning, development of legislation and accessing of mental health services for African/ African Caribbean communities in Lambeth.

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Alexei's Personal Experience (Community Researcher):

The past ten months of working on the Recovery Project have been a journey of highs, lows and in-betweens. There have been major team changes, successes and set-backs, and lots and lots of hard work. It has also been a very educational experience, for instance, giving me an all-round understanding of what Community Research is all about and how it is done. I have gained confidence in working in the field of mental health, and now feel that I can enjoy what I do for a living.

Before the project, I had no prior experience of this kind of in-depth research. Unless exploring the library during college coursework can be counted... Going into the research, I didn't feel totally confident that I would be able to do it. But I was relieved that us five male Volunteers weren't just expected to 'get on with it' from the start, but were given specific training in our planned methods of data collection by Belonwu, and in the specifics of what to do at each stage of the research by UCLan workers Joanna Hicks and Manjit Bola. From these UCLan workshops I also managed to complete the work for a University Certificate in Community Research, for which I achieved a confidence-boosting Merit. All of this training helped to give a sense of direction and an ability to break it all down into bite-size chunks, making it all a whole lot easier to tackle. This motivated me and strengthened my abilities within team discussions, as well as within listening and communication.

After a large part of the team left for other pastures, it was just Guilaine, Lloyd and I left to do the work. At this point Lloyd and I became official employees on Fanon's payroll, giving me an added sense that my contributions are valued.

When it came to the actual interviews, I was again reminded of my abilities to communicate, but this time it was a more relaxed experience of listening and responding, meeting the participants, and making sure that they were comfortable talking to me. Through these often impassioned conversations, they shared some of their deepest experiences and thoughts while I listened and facilitated. I felt a sense of trust, and responsibility to ensure that their trust was not in vain. Many said afterwards that they had really enjoyed the interview, and expressed gratitude for having their experiences heard and taken seriously. I found this really moving, and hope that more people in this position can feel that they are also being listened to; that their experiences do count.

With the departure of the rest of the team in December, near the end of analysing the findings, I was on my own for a month while new staff were being recruited. This was stressful for me, but I really wanted to carry on and help bring it all to a successful conclusion, so that all the contributions of the various people involved would not be wasted. In meetings with Joanna Hicks and Nicholas Campbell-Watts (Fanon Director), I was assured that five new Community Development Workers would be joining me soon. The first to arrive was Abdi, in early February, followed closely by Elicia, Pauline, Ian and David. We immediately launched headlong into re-analyzing the interviews and writing the full report from scratch.

During this period, I developed my ability to work in a closely-knit team, frequently discussing report progress and general issues in Mental Health. I improved my computer software skills, working with Word, Excel and Outlook Office programs. This being the most hectic and personally involving part of the project for me, I also learned to better juggle my social life with my various roles within the Mental Health field.

We quickly developed good team rapport, which greatly eased all the stresses and strains experienced to meet our fast-approaching deadline. I have to say, it really was a mammoth task to complete in just a month and a half, but we managed to do it. Looking back, I am in awe of our team for actually taking on and accomplishing this vital report.

My most proud accomplishment has been a re-working of the Table of Qualitative Findings (in the 'Qualitative Analysis' section). I re-arranged it so that, instead of just listing off 'who said what' with no obvious relationships between the ideas in neighbouring columns, the table shows the correlations between all of the participants' different ideas and experiences of Recovery. I hope that this arrangement of the table is much more user-friendly and informative to anyone who chooses to read it. While this task was hugely time-consuming, it was enjoyable to get back to the methodical and intricate ways of working that I remember from my college days.

In short, the whole progression of the project has been a journey of getting back in touch with my own abilities, and of becoming more able, and feeling more able, to re-enter full-time employment. I have come to enjoy my work again, and have been able to operate both in the community and in an office environment, being a trusted member of the team. I have developed the aspiration and ambition to continue working within Mental Health services, and to continue the positive developments that we have begun in the Recovery Project.

I am enormously grateful to everyone who has been a help at any stage of this journey, from my various team members and those who helped the project along, to all of the participants, without whom none of it would have been possible. Thank you, one and all.

Appendices:

APPENDIX I

University of Central Lancashire, Centre for Ethnicity and Health

Ethics Proforma

Section 1:

Name of Group	Southside Partnership Fanon
Address	31-33 Lumiere Court, 209 Balham High Road , London SW17 7BQ
Name of Support Worker	<i>Joanna Hicks</i>
Date:	<i>20th July 2007</i>

Section 2:

What kind of work does the group intend to do as part of this project?	<p><i>We are carrying out a research project aiming to investigate how African and African-Caribbean perspectives on recovery could improve current mental health provision within Lambeth.</i></p> <p><i>Specifically our research questions are:</i></p> <ul style="list-style-type: none"><i>• How do Black mental health Service Users in Lambeth define recovery and what would pathways to recovery look like from their accounts?</i><i>• What factors facilitate recovery and help people stay well from a Black mental health Service User' perspective?</i><i>• What can be learnt from those definitions and perspectives which could improve the design and delivery of mental health services in Lambeth?</i>
How do they intend to do this?	<p><i>We intend to use mixed method through the use of a combination of interviews, focus group discussions and questionnaires. Furthermore, a discussion group will be held to raise awareness and get a feedback on the tools. We aim to recruit about 100 respondents in total from the Lambeth borough. Each interview participant will</i></p>

	<p><i>be automatically offered the opportunity to fill out a questionnaire which will mainly capture demographic information (and will include UCLAN core questions in addition to gathering the participants' recovery expectations). The researcher will go through the questionnaire with each participant wishing to complete a questionnaire.</i></p> <p><i>The questionnaire may also be used as a stand alone data collection tool.</i></p> <p><i>The interview will be semi-structured and guided by an interview schedule. Interviews will last no longer than 1 hour and the questionnaire component no more than a half hour.</i></p>
<p>Who will the respondents be?</p>	<p><i>Our target population will be service Users from African and African Caribbean backgrounds (including those of mixed Heritage) who fulfil the following criteria:</i></p> <ul style="list-style-type: none"> <i>• Are users of voluntary community mental health services (recruitment sites)</i> <i>• Have capacity to give (informed) consent</i> <i>• Are male</i> <i>• Are aged between 18 and over</i> <i>• Are normally Lambeth Residents.</i> <p><i>When recruiting participants, researchers will approach key workers to ensure that those with a history of violence/self harm are not included.</i></p>
<p>Who will they get to do the work?</p>	<p><i>The work will be carried out by a team of six community researchers (volunteers), who will be supported by a Community Research Coordinator.</i></p> <p><i>The project manager will offer quality assurance both data collection and data analysis and offer methodological support to the research team.</i></p>
<p>Where they will undertake the work?</p>	<p><i>The work will be undertaken at the Fanon Resource Centre (Interviews) and the Southside Partnership Fanon head office (Data analysis); or at resource centres normally used by the respondents.</i></p> <p><i>A private room with access to panic alarms and assessable to staff in case of emergency will be used (see risk assessment).</i></p>

<p>How will those who are doing the work be supported and supervised?</p>	<p><i>The six community researchers will be supervised by a community research coordinator. The project will be managed by the CDW and will be further supported by Johanna Hicks from University of Central Lancashire. Additional support and supervision will also be supplied by the Lambeth DRE Steering Group and the director of Fanon.</i></p> <p><i>Apart from day-to-day coordination, there will be formal team meetings every week and monthly supervision sessions. Appropriate training will be provided to build the necessary competence and confidence in the researchers. In addition to the UCLAN MH CE Workshops, we have identified the need to train the researchers in interviewing skills, boundaries and basic IT. More training will be included as they are identified taking into account the budget and time constraints.</i></p>
<p>How they will ensure that participants in the project have given consent? You should have an information sheet about the project which is read out and given to potential participants which explains to them (a) what the project is about. (b) that participation is voluntary (c) what will happen to the information that they provide (d) that they can stop the interview at any time and (e) that they do not have to answer any questions that they do not want to.</p> <p>Note: <i>If the research is using more than one method, then we need information sheets and a discussion of the risks for each. The info sheet and</i></p>	<ol style="list-style-type: none"> <i>1. Participants will be given information sheets which will give them an overview of the project and explain their rights and our responsibilities;</i> <i>2. Given the potentially low level of English literacy, the researchers will read out the information sheets prior the interview to ensure each participant is aware of what inclusion in the project involves. Participants' rights will be stressed, including their right to confidentiality and voluntary participation;</i> <i>3. They will also be required to fill and initial a consent form which will be retained by the research team and stored away from their interview data.</i> <i>4. As the consent form will contain identifiable data, it will be stored separately from the participants' questionnaires and/or interviews.</i> <i>5. We aim to obtain information only from persons aged 18 years and above who are capable of giving consent. In line with the Mental Health Capacity Act we will assume that every participant has capacity</i>

<p><i>the risks will not be the same for 1:1 interviews and for focus groups, for instance.</i></p> <p>Note 2: <i>Parental (or responsible adult e.g. teacher if the work is happen in school) consent will be required if any subjects to be interviewed are under 16. Generally speaking, most projects should not be working with under 16's.</i></p>	<p><i>unless there are reasons to think they do not (see risk assessment).</i></p>
<p>Please enclose the information sheet and confirm that it addresses issues (a), (b), (c), (d) and (e) above</p>	<p>Information sheet enclosed (<input checked="" type="checkbox"/>) tick to confirm</p> <p>Issue (a) covered (<input checked="" type="checkbox"/>) tick to confirm</p> <p>Issue (b) covered (<input checked="" type="checkbox"/>) tick to confirm</p> <p>Issue (c) covered (<input checked="" type="checkbox"/>) tick to confirm</p> <p>Issue (d) covered (<input checked="" type="checkbox"/>) tick to confirm</p> <p>Issue (e) covered (<input checked="" type="checkbox"/>) tick to confirm</p>
<p>How they will the project ensure confidentiality?</p> <p>Note: you will not usually need to know (or collect) the names or addresses of respondents. If you know them already, or if you are going to ask people their names as a matter of courtesy, these should not be recorded on the questionnaires or the notes that relate to the interview.</p> <p>Note: you cannot guarantee confidentiality to anyone taking part in a focus group. You can request that people keep things within the group, but you cannot guarantee that the will. This must be</p>	<ol style="list-style-type: none"> 1. <i>The research team has been trained rained on issues of confidentiality;</i> 2. <i>Interview and focus group sessions will be held in private meeting rooms at the Fanon Resource Centre or the resource centres where the respondents normally attend;</i> 3. <i>The names of participants will not be recorded in our questionnaires, other research tools or our reports;</i> 4. <i>Information will be recorded in such a way that they cannot be attributable to any particular individual. For instance by using pseudonyms and/or interviews numbers</i> 5. <i>Data collected during interviews, focus groups and completed questionnaires will be kept in secure and lockable cabinets which may only be accessed by authorised members of the research team.</i> 6. <i>Electronic data will be stored in password protected files and computers within the Southside Partnership Fanon data base;</i> 7. <i>Access to the raw data will be restricted to</i>

<p>made clear to people who agree to participate in focus groups.</p>	<p><i>authorised members of the research team, Southside Partnership Fanon and UCLAN.</i></p> <p>8. <i>Raw data will be retained for three years for re-analysis and verification purposes after which it will be destroyed.</i></p> <p>9. <i>Participants, especially for the focus group will be made aware of the limits of confidentiality (see risk assessment).</i></p>
<p>How will data generated by the project be handled and stored?</p>	<p>1. <i>Access to the data will be restricted to authorised members of the research team, Southside Partnership Fanon and UCLAN;</i></p> <p>2. <i>Data collected will be kept in secure cabinets within the project's office;</i></p> <p>3. <i>Electronic data will be stored in password protected files within the Southside Partnership Fanon data base;</i></p> <p>4. <i>All interview notes, audio records, questionnaires and notes will be destroyed at an agreed date after publishing the final report.</i></p> <p>5. <i>Requirements under the data protection act will be met; this will be facilitated by our HR department.</i></p> <p>6. <i>Anonymised raw data will be stored for a maximum of 3years for data verification and reanalysis purposes.</i></p>
<p>What risks are there? How will risks be identified and managed?</p> <p>Note you need to think about risks to researcher and volunteers and risks to participants. For some people, simply taking part in the research may be a risk (e.g. if the parent of a young Muslim woman finds out that she has been talking to someone about drugs). For others, particular situations may be risky (e.g. if you are using ex-drug users to work on the project, are you putting them at risk of</p>	<p><i>The CDW and the research coordinator have the primary responsibility for identifying and managing risk. Specific risks will be identified and the action plans for managing them put in place at the planning stage of every interview or focus group session. Risk assessments will also be integrated into team meetings and supervision sessions.</i></p> <p><i>The following risks have been identified and procedures for managing them put in place:</i></p> <p><i>Participant privacy:</i></p> <p><i>The interview will take place in an interview room at Fanon Resource Centre, and centres normally used by the respondents. We shall ensure that such rooms are private and only the respondent and researcher(s) are in attendance.</i></p>

<p>relapse by asking them to go back into situations where drugs are being sold or used? If something gets stolen from an office, will they get blamed for it [regardless of whether or not they did it] because everyone knows they are a drug user?). Are the interviewees particularly vulnerable or frail? Are interviewers likely to be vulnerable to allegations of misconduct?</p> <p>Are the risks of carrying out or participating in individual interviews different from those of taking part or running a focus group? They probably are, and you need to show that you have thought about and addressed this.</p> <p>THIS IS ONE OF THE MOST IMPORTANT SECTIONS OF THE FORM. YOU MUST THINK CAREFULLY ABOUT WHAT THE POSSIBLE RISKS ARE AND ABOUT WHAT STEPS CAN BE TAKEN TO REDUCE AND MANAGE THEM. THE ETHICS COMMITTEE UNDERSTANDS THAT IT IS USUALLY IMPOSSIBLE TO ERADICATE EVERY RISK, BUT THE ETHICS COMMITTEE MUST BE</p>	<p><i>Informed Consent:</i></p> <p><i>In accord with the mental capacity act every participant will be assumed to have capacity to give informed consent unless there is evident sign that they may not E.g. : Difficulty in understanding what is being said to them or difficulty in expressing their understanding of the project.</i></p> <p><i>In case of doubt participants will not be recruited.</i></p> <p><i>Prior the start of the interview, a researcher will go through the consent form with the participant and ensure he is fully informed.</i></p> <p><i>The participant will then be requested to sign a consent sheet which will be retained by the researcher.</i></p> <p><i>Specific consent will be sought prior recording the interview and for focus group participation.</i></p> <p><i>Participants will be fully debriefed on all aspects of the project by asking to provide some information on their experience of taking part.</i></p> <p><i>Confidentiality</i></p> <p><i>Confidentiality will be observed at all times and identifiers will be removed from public documents .However, Focus group attendees will be made aware that confidentiality cannot be guaranteed , this will be indicated on the consent form.</i></p> <p><i>Raw data will not be made available.</i></p> <p><i>Data Protection Act requirements will be observed.</i></p> <p><i>Once the project completed, focus groups notes/observations, interview notes and completed questionnaires will be retained for a maximum of 3 years for reanalysis purposes. They will be stored as archives and will only be accessible through direct and expressed authorisation from the director.</i></p>
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SATISFIED THAT ANY RISKS ARE REASONABLE, AND THAT STEPS HAVE BEEN TAKEN TO MINIMISE THEM

It may not be necessary for every researcher to be police (CRB) cleared, but it will be necessary where interviewers are going to interview young (under 16's) or vulnerable (e.g. elderly, mental health or drug service users) groups unless such interviews are going to take place in an environment where the interviewers are appropriately supervised. The fact that a potential interviewer has a conviction should not automatically bar them from taking part in the research as an interviewer, but it may mean that they need additional supervision or that they should not be allowed to carry out interviews with certain groups of people – it will depend on the nature and seriousness of the conviction.

Voice recordings during interviews will be destroyed after transcription. Transcription material will be password protected and stored electronically for three years. Again, access will be password protected and solely via director's authorisation.

Participant safety:

We do not anticipate distress occurring during the interview but it is possible that some participants may become uncomfortable when revealing sensitive information. We also do not expect any violence or exploitation occurring from the researchers.

A number of precautions will be put in place to minimise possible discomfort and protect participants. These include:

- Firstly, potential participants will be introduced to the research team and rapport will be built prior to seeking participation.*
- Secondly, potential participants will be informed of the interview schedule and of the type of information that will be required from them.*
- Pilot interviews will be conducted to test the robustness of the measures and monitor participants' reactions to the questions and adjustment(s) will be made to the interview schedule if necessary.*
- Participants will be free not to answer any question (without justifications) and will have the right to withdraw from the study at any point.*
- In the event of a participant becoming visibly distressed, the interview will be terminated and we will encourage him to consult his key worker; and more support requested if considered necessary.*

- *Every participant will be asked to give some feedback on their experience of taking part in the research project at the end of the interview.*
- *The researchers will be CRB cleared and anyone with serious forensic history, especially crimes to the person, will be closely supervised.*
- *The interviews and focus groups though private, will be held within the vicinity of other staff and during normal office hours to enable indirect monitoring by staff.*

PROTECTION OF RESEARCHERS

Researchers' personal safety:

- *Researcher will be trained on personal safety issues and will be encouraged to walk away from situation they do not feel comfortable with;*
- *Researchers will also be trained on Boundaries to minimise false allegations;*
- *Researchers will be debriefed daily and supervised weekly during the field work stage;*
- *When on site , staff will be made aware that interviews are being carried out so that some degree of monitoring can occur outside the research team;*
- *Rooms where the interviews will be carried out are equipped with panic Buttons and researchers will be encouraged to use them;*
- *Researchers will be trained in the health and safety aspects of each site e.g. fire exits, emergency procedures etc;*

	<ul style="list-style-type: none"> • <i>Participants known to the recruitment site for violence will not be included in the project (key workers will assist in identifying potentially high risk participants);</i> • <i>Researchers will not carry out more than 2 interviews per day so minimize effects on them.</i>
<p>Please confirm the make up of the steering group</p>	<ol style="list-style-type: none"> 1. <i>Denis O'Rourke, Asst Director, Community Adult MH Team, Lambeth;</i> 2. <i>Denise Bob, Race Equality Lead, Lambeth;</i> 3. <i>Nicholas Campbell-Watts, Director, SSP Fanon;</i> 4. <i>Paula Asquith; DAAT;</i> 5. <i>Patrick Gillespie, Borough Director, SLAAM;</i> 6. <i>Chandra Fowler, Coordinator, National SU Network;</i> 7. <i>Dominic Walker (SU), Project Manager, Catch-a-Fiya;</i> 8. <i>Patrick O'Dwyer, Health Adviser to the Government Office in London;</i> 9. <i>Kamel Chahal, Clinical Psychologist;</i> 10. <i>Dr. John Curran, Med. Anthropologist, SLAAM;</i> 11. <i>Dr. Andrew Forrester, Consultant Forensic Psychologist, Brixton Prison;</i> 12. <i>Nigel, Head of Health Care, Brixton Prison;</i> 13. <i>Nicola Wilson, Commissioner, Adult MH, Lambeth PCT;</i> 14. <i>Robert Murray, Forensic Director, SLAAM;</i> 15. <i>Lloyd Lindsey, Service User;</i> 16. <i>Guilaine Kinouani, Community Development Worker, SSP Fanon;</i> 17. <i>Belonwu Ezenwa, Research Coordinator, SSP Fanon.</i> 18. <i>Joanna Hicks, UCLAN.</i>
<p>How often does the Steering Group meet? It needs to meet often enough to both guide the</p>	<p><i>Six weekly</i></p>

<p>research and keep it on track, and to pick up on any ethical issues that may arise. Generally we think that steering groups should meet at least once every six weeks, with additional meetings to be held at critical points (e.g. to decide upon the research focus; to comment on questionnaire design; to review early fieldwork progress and feedback; to consider early findings; to help shape report; to consider recommendations; to plan dissemination of findings.)</p>	
<p>Is the Steering Group clear that it has a responsibility for helping to manage the ethical issues that may arise as a result of running this project?</p>	<p>Yes</p>

Section 3: To Be Completed By UCLan internal ethics committee

Date received:	
Reviewed by:	
Decision:	

APPENDIX II - Questionnaire

Core Questions:

- 1.1 Age last birthday:**
- 1.2 Gender:**
- Male
 - Female
 - Tran gendered
- 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 (please explain)
 -
- 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?

Spoken **or** **signed:**
.....

Written:
.....

1.7 Which languages are you fluent in?

Spoken **or** **signed:**
.....

Written:
.....

1.8 What is your religion: None
Christianity
Buddhism
Hinduism
Judaism
Islam

Sikhism
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

2. Service use Length:

How long have you received any form of mental health services?

- Less than 1 year
- 1 year or more but less than 5 years
- Between 5 – 10 years
- More than 10 years

3. Recovery expectations and stages

Based on your personal understanding of "Recovery" as discussed earlier, Please indicate your level agreement or disagreement with the following statements, by placing a circle around the statement that best describes what you think.

I have heard or thought about recovery (before today)

I strongly agree, I agree, I don't know, I disagree, I strongly disagree

I believe that it is possible to recover

I strongly agree, I agree, I don't know, I disagree, I strongly disagree

I am committed to my recovery and making plans to take action very soon

I strongly agree, I agree, I don't know, I disagree, I strongly disagree

I am on the path to recover and/or maintaining my gains

I strongly agree, I agree, I don't know, I disagree, I strongly disagree

I do not believe I have any need to recover

I strongly agree, I agree, I don't know, I disagree, I strongly disagree

4. RECOVERY ENHANCING SUPPORT (Formal Support)

Please circle one answer per statement					
SA – If you strongly agree with the statement A – If you agree with the statement N – If you are not sure , or neither agree or disagree, or you are neutral . D – If you disagree with the statement. SD – If you strongly disagree with the statement					
E.g. : Self-help or user-run services are important to my Recovery.	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Culturally specific services (services run for and by black people) In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Clubhouse/Resource Centres In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Residential services for people with mental health needs In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Hospital inpatient services In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Outpatient services In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Community mental health team In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Home treatment/crisis resolution team In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
talking therapies In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Medications/medication management In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Peer support & other service user networks In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD
Other..... In the last 2 years , have you used this type of services Yes/ No	SA	A	N	D	SD

5. RECOVERY ENHANCING SUPPORT (Informal Support)

For each of the following questions you should circle one of the answers: SA – If you <i>strongly agree</i> with the statement A – If you <i>agree</i> with the statement N – If you are <i>not sure</i> , or neither agree or disagree, or you are <i>neutral</i> . D – If you <i>disagree</i> with the statement. SD – If you <i>strongly disagree</i> with the statement					
E.g. : I am confident that ... will/has help me recover	SA	A	N	D	SD
My family Do get support from your family Yes / No	SA	A	N	D	SD
My friends Do get support from your friends Yes / No	SA	A	N	D	SD
My neighbours Do get support from you neighbours Yes / No	SA	A	N	D	SD
Non-prescribed medication Do use non prescribed medication Yes/ No	SA	A	N	D	SD
Other substances Do you use other substance Yes /No	SA	A	N	D	SD
Spiritual or religious activities Do you practice any religious or spiritual activity Yes/No	SA	A	N	D	SD
User groups Do you attend any user group Yes/ No	SA	A	N	D	SD
My traditions Do you uphold /carry on any tradition Yes / No	SA	A	N	D	SD
Learning about my cultural heritage Do you learn about your cultural heritage Yes /No	SA	A	N	D	SD
Other Do you Yes / No	SA	A	N	D	SD

6. ELEMENTS OF RECOVERY AND RECOVERY ENHANCING SERVICES

For each of the following questions you should circle one of the answers:
SA – If you **strongly agree** with the statement
A – If you **agree** with the statement
N – If you are **not sure**, or neither agree or disagree, or you are **neutral**.
D – If you **disagree** with the statement.
SD – If you **strongly disagree** with the statement

	SA	A	N	D	SD
1. Having a positive sense of personal identity beyond my diagnosis/mental illness/distress is important to my recovery					
2. Having a sense of meaning in life is important to my recovery.					
3. Having hope is important to my recovery.					
4. Having up-to-date knowledge about mental disorders and the most effective treatments is important to my recovery.					
5. Being able to self-manage symptoms/distressing experiences and avoid setbacks is important to my recovery.					
6. Improving my general health and wellness is important to my recovery.					
7. Being active in directing my own recovery is important to my recovery.					
8. Having my rights respected and upheld is important to my recovery.					
9. Mutual self-help/peer support is important to my recovery					
10. Being involved in personally meaningful activities is important to my recovery.					
11. Being involved in, and part of, the larger community is important to my recovery.					
12. Having positive relationships is important to my recovery.					
13. Identifying and building on my own personal strengths is important to my recovery.					
14. Developing new skills is important to my recovery.					

15. Having my basic needs met is important to my recovery.	SA	A	N	D	SD
16. Having a sense of control over my life and feeling empowered is important to my recovery.	SA	A	N	D	SD
17. Spirituality is important to my recovery.	SA	A	N	D	SD
18. Taking on, and succeeding in, ordinary social roles is important to my recovery.	SA	A	N	D	SD
19. Being able to challenge stigma and discrimination is important to my recovery.	SA	A	N	D	SD
20. Taking on new challenges and moving out of my comfort zone is important to my recovery.	SA	A	N	D	SD
21. Having positive role models is important to my recovery.	SA	A	N	D	SD
22. Having assistance when I am in crisis is important to my recovery.	SA	A	N	D	SD
23. Intimacy and sexuality are important to my recovery.	SA	A	N	D	SD
24. Having helpers who really care about me and my recovery is important to my recovery.	SA	A	N	D	SD

APPENDIX III : - Interview Guide - Recovery Project

1. ASPIRATIONS

We /I would like to start by asking you to think about what you think would make you happier and help you lead a better life. The next few questions will therefore focus on your desires and aspirations.

*In an ideal world what would you be doing?
What would be your ultimate achievement(s)?
What do you need to get there?*

2. SENSE OF HOPE AND OPTIMISM

In the next few questions I/we will be trying to find out about your sense of hope and about your outlook on life.

*Do you think that things are going to get better or that there are more positive things to come from life, why, why not?
How would you stay positive if things went wrong?
How do you imagine your life 5 years from now?*

3. STRENGTH AND RESILIENCE

We/I would like you to now think about all the things that give you strength and allow you to keep going and to stay well, so please think about where you get your resilience from.

*What gives you the strength to keep going?
What are the things /people that supports you in a time of adversity?
What are the types of things you do on a regular basis to stay well/healthy
What do you absolutely need to stay on top of things or have a sense of control?*

4. EXPLANATORY MODELS

The questions below will be used to understand the beliefs you hold with regards to your health. Those beliefs have been linked to service use experience, preferred modes of support and recovery expectations.

There is no right or wrong answers; we will not judge you based on what you say.

*What in your view is a mental health condition or a mental health problem?
Do you think you have a mental health condition? Why? / Why not? If no go to section 7
What is it?
When did it start?*

*What do you think has caused it?
How do you manage it?*

If no to 6.1 (participant does not think that he has a mental health condition)

7. ALTERNATIVE EXPLANATORY MODELS

*What do you think has lead you to get into contact with the mental health services?
What do you think were the causes?*

5. BARRIERS TO WELL BEING AND/OR RECOVERY

Having thought about the things that give you strength and keep you well we/I now would like you to give some thoughts to the things that make it difficult for you to stay well or make you doubt that you will recover.

*Are there things that make your condition or situation worse, what are they?
What in your view are the barriers to your well being and sense of well being?
Are there situations or events that make you think that it is not possible to recover, what are they?*

8. RECOVERY MEANING AND CONCEPTUALISATIONS

In this final part of the interview I/we will be concentrating on what recovery means to you. The last few questions will try and gauge your understanding of the idea of Recovery and assess its importance in your life.

*What is your personal understanding of the word Recovery?
How important is Recovery to you and why?
Thinking about your situation, how meaningful or useful do you find the idea of recovery and why?
As a Black man, do you think that your Recovery needs would be different, how so /why not?
What would be the most important steps to take to recover?*

QUESTIONNAIRE COMPONENT

1. Core 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 transsexual

APPENDIX IV: -

Highest Qualitative Data Percentages

Barriers – What didn't help? (#) = number of respondents	Percentage (+/- 0.5%)
Stigma/ labelling/ society perception (8)	36%
Increased isolation by living or moving to new area/ Loneliness (7)	32%
Racism/ Discrimination (3)	14%
Homelessness (3)	14%
Negativity (family & friends) (3)	14%
Drug and alcohol use (3)	14%
Medication effect (2)	9%
Lack of focus (2)	9%
Unemployment (2)	9%
Family problems/ family separation (2)	9%

Facilitative factors – What helped? (#) = number of respondents	Percentage (+/- 0.5%)
Sport/ Exercise/ Physical health (9)	41%
Support network - (e.g. from family, friends etc) (8)	36%
Optimism/ positivity (7)	32%
Relationships/ Family life (with children) - (6)	27%
Medication (6)	27%
Spirituality/ God's support (6)	27%
Structured activities/ keeping busy (6)	27%
Ambition/ future aspiration/ goals (5)	23%
Education (5)	23%
Employment (5)	23%
Being or staying focused (4)	18%
Socialising/ Having good friends/ Positive people (4)	18%
Ability to be responsible (e.g. financial responsibility) (3)	14%
Independence (3)	14%
Hope (3)	14%
Self esteem/ self believe (3)	14%
Self reflection/ self analysis/ self awareness (3)	14%

Contact with family (not for support only) (2)	14%
Culturally specific services (2)	9%
Understanding one's rights in the hospital (2)	9%
Healthy diet (2)	9%

Conceptualisations – What is Recovery? (#) = number of respondents	Percentage (+/- 0.5%)
Getting back to a normal state of mind – (Getting back to the place where you were originally/ Regain past potential) (10)	45%
Functional/ contributing to society/ Having a purpose (7)	32%
Being able to move on/ working towards a goal/ moving forward (5)	23%
Feeling comfortable/ enjoying life - (no worries including financial) (3)	14%
Happiness (3)	14%
Assistance from support services - 'like AA roadside repair'(3)	14%
Having something to look forward to (2)	9%
Not having to take medications again (2)	9%
Independence (2)	9%
Shift in value systems/ Egalitarian (equal) approach to people (2)	9%

Notes:

- Due to the small sample size, there is a limitation in terms of the level of accuracy that is appropriate to the data. Therefore, **these percentages have been rounded to the nearest 1%**
- Because each participant has contributed a number of the above points, and it is not indicated whether two factors were stated by the same participant or not, **these percentages cannot be added together to give reliable statistics.**

APPENDIX V: List of Factors Important in Recovery

1. Having a positive sense of personal identity outside my illness is important to my recovery
2. Having a sense of meaning in life is important to my recovery
3. Having my rights respected is important to my recovery
4. Having positive relationships is important to my recovery
5. Having a sense of control and feeling empowered is important to my recovery
6. Improving my general health and wellness is important to my recovery
7. Being involved in personally meaningful activities is important to my recovery
8. Having assistance in a crisis is important to my recovery
9. Having hope is important to my recovery
10. Identifying and building on personal strengths is important to my recovery
11. Having my basic needs met is important to my recovery
12. Support from friends is important to recovery
13. Taking on new challenges is important to my recovery
14. Having helpers who really care is important to my recovery
15. Being active in directing my own recovery is important to my recovery
16. Developing new skills is important to my recovery
17. Succeeding in ordinary social roles is important to my recovery
18. Being able to challenge stigma and discrimination is important to my recovery
19. Having positive role models is important to my recovery
20. Culturally specific services are important to my recovery
21. Being able to self-manage symptoms and avoid setbacks is important to my recovery
22. Peer-support is important to my recovery
23. Being involved in the larger community is important to my recovery
24. Family support is important to recovery
25. User groups are important to recovery
26. Learning about my cultural heritage is important to my recovery
27. Spiritual or religious activities are important to recovery
28. Spirituality is important to my recovery
29. Intimacy and sexuality are important to my recovery
30. Residential services are important to my recovery
31. Having up to date knowledge about mental health is important to my recovery
32. Clubhouse /resource centres are important to my recovery
33. Community Mental Health Teams are important to my recovery
34. Peer support and other service user networks are important to my recovery
35. My traditions are important to recovery
36. Talking therapies are important to my recovery
37. Outpatient services are important to my recovery
38. Home treatment / crisis resolution teams are important to my recovery
39. Medications / medication management are important to my recovery

40. Support from neighbours is important to recovery
41. Hospital inpatient services are important to my recovery
42. Other substances are important to recovery
43. Non-prescribed medication is important to my recovery

APPENDIX VI:



Can we ever recover from what they call “**mental illness?**”

We’re looking for a:
Community Research Coordinator
(£22 000 part time pro rata)
to help us find out

Fanon, in collaboration with the Catch-a-Fiya Network is about has started a community research project looking at what keep men from African and Caribbean backgrounds on the **road to recovery**.

An opportunity has now arisen for a Research coordinator to join the project on a fixed term basis for 4 months from October to January. Internal secondment will be considered.

You will support a team of volunteer community researchers and contribute to a variety of research and development activities.

Applications are in the form of a letter of interest indicating why you think you'd be able to do the job. If you can, please refer to the person specification and address, fax or email for letter to the HR administrator.

The closing date for receipt of letters of interest is September 19th @ 17h00. Interviews to be held shortly thereafter.

For more information or an application pack, please contact **Guilaine** on 020 8772 6176.



Train as a Volunteer Service User Researcher!

Do you think that **mental health services** could be improved for people from **African and African Caribbean communities?**

We think that **listening to what Service Users have to say** can help to improve services

To find out more,
contact **Guilaine** on
020 8772 6176

If you are interested in helping, we would love to hear from you!

Fanon is being funded by the National Institute for Mental Health Excellence to undertake research looking at what **recovery** means for African and African Caribbean men using mental health services in Lambeth..

We are looking for **people of African and African Caribbean origin** who have used mental health services and would be **interested in training as community researchers** to collect the stories of other users and help us to improve services.

APPENDIX VIII:



Can we ever recover from what they call “mental illness?”

If you are a **black man of African or African Caribbean background** and you use **mental health service**: **You must be able to: your views.**

Fanon, in collaboration with you think will be of benefit to people of all backgrounds or

- Volunteer at least 4 hours a week for up to 9 months
- Be committed to improving mental health services
- Interested in your personal development

In return we will provide:

- Excellent support and training
- Your expenses paid including travel and lunch (where appropriate)
- The opportunity to make a real difference

Join us for a friendly discussion and some refreshments
on Monday 30th April
2.00pm -4.00pm

At Fanon Resource Centre: 107 Railton Road
Brixton SE24 0LR

For more information, contact **Guilaine** on 020 8772 6176 or just pop in help us to get this project started.

Appendix IX: - Quantitative Tables

Age

Age	Number	Percentage
19-21	2	7
22-24	5	17
25-29	5	17
30-39	6	21
40-49	6	21
50+	5	17
Total	29	97
Missing	1	3.3
Total	30	100

Ethnicity

Ethnicity	Number	Percentage
White & Black Caribbean	1	3 %
White & Black African	4	14 %
Caribbean	15	52 %
African	8	28 %
White & Asian	1	3 %
Chinese & Afro- Caribbean	1	3 %
Total	30	100 %

First language

Language	Number	Percentage
English	24	81 %
Patois	2	7 %
Krio	1	3 %
Shona	1	3 %
Timini	1	3 %
Acholi	1	3 %
Total	30	100 %

Born in or outside the UK

Number	Born in the UK	Percentage
17	Yes	57 %
13	No	43 %
Total	30	100 %

Length of time in the UK (if born outside)

Length of time in the UK	Number	Percentage
1-5 years	1	8 %
6-10 years	2	15 %
11 years or more	10	77 %
Total	13	100 %

Religion

Religion	Number	Percentage
Christian	22	73 %
Rastafarian	4	13 %
Muslim	2	7 %
None	2	7 %
Total	30	100 %

Disability

Disability (Yes/ No)	Number	Percentage
Yes	17	57 %
No	13	43 %
Total	30	100 %

Length of time in the mental health services

Length of time in service	Number	Percentage
Less than 1 year	4	13 %
1-5 years	10	34 %
5-10 years	7	23 %
More than 10 years	9	30 %
Total	30	100 %

QUOTES: WHAT DOES RECOVERY MEAN TO YOU?

“The only thing wrong with Recovery is leaving everyone else behind”

“If you have a problem, don't give up. Put your hopes high where God can see them so he won't have a reason not 2 help you”

“Recovery means coming out of this, it means, like when a car breaks down and you repair it like the AA or someone, that's Recovery”

“Recovery is moving on to new pastures and a firm foundation. Peace”

“Recovery is journey of discoveries”

**For more information on Recovery or other Community Development Work,
please contact the Community Development Team:**

Fanon Resource Centre Lambeth
107 Railton Road
London
SE24 0LR

Telephone: 020 7737 9837

Fax: 0207 737 1861

Email: cdw@southsidepartnership.org.uk

Website: www.southsidepartnership.org.uk