Norfolk and Suffolk **NHS**

NHS Foundation Trust

Summary of key findings

Open Mind Dialogue Workshops around BME communities and mental health in Suffolk, Saturday, 27 September 2014.

OPEN MIND

your wellbeing in mind

Suffolk Refugee Support

CARIBBEAN & AFRICAN COMMUNITY HEALTH SUPPORT FORUM

Norfolk and Suffolk NHS Foundation Trust in partnership with Caribbean and African Community Health Support Forum and Suffolk Refugee Support.

Contents:

1. Background

Regardless of ethnic background, everyone who is in need of mental health services, or cares for someone who does, should have equitable access to effective interventions, and equitable experiences and outcomes. However, there is growing body of research literature over the past 50 years suggesting that Black and Minority Ethnic (BME) communities have more adverse experiences and negative outcomes within mental health care compared to the majority population in relation to both accessing services and their experiences of care (JCPMH 2014).

A recent study of people's experiences of the Care Programme Approach found that African Caribbean respondents had generally poorer experiences than respondents overall (Gould, 2012).

It is also important to recognize that disadvantage and discrimination have an adverse effect on the wellbeing and mental health in all BME communities. At the same time, any specific inequalities for BME communities must also be seen within the context of the health inequalities experienced by anybody suffering with a mental health problem. In effect this contributes to the wider differences that exist across ethnic groups both in morbidity and mortality again repeatedly documented in the UK (Lethal discrimination 2003, NHS Information Centre for Health and Social Care 2011, ONS 2012).

The joint commissioning panel for mental health recognises that there are significant and persistent ethnic inequalities in service experience and outcomes, BME communities report higher levels of dissatisfaction compared to the white majority and BME groups are over-represented in some forms of mental health service (that is, under a more restrictive regime such as the criminal justice system) and others under-represented (JCPMP, 2014).

Although we have enough evidence nationally to suggest the huge gap in services when it comes to BME communities, local mental health services in Suffolk and Norfolk have yet to engage with its diverse communities and provide an environment where their voices can be heard and listened to. This is the very beginning of challenging the use of the lazy term known as "hard to reach" group when it comes to referring to or engaging with our BME communities. Apart from the fact that this is a somewhat stigmatizing description, it implies homogeneity within particular groups or communities that may not necessarily exist.

Therefore the main purpose of this pilot workshop was to create an opportunity for an open mind discussion to take place between local BME communities within Suffolk, including people seeking asylum or refuge, and voluntary and statutory organisations. The intention is that a series of other Open Mind workshops will be organised throughout Suffolk and Norfolk during 2015, and that the workshop on the 27 September 2014 will be used as a pilot.

The main findings from the workshop revealed issues such as lack of information, lack of cultural sensitivity and understanding when it comes to services in meeting needs of BME groups, lack of understanding leading to stigmatization and discrimination, and lack of trust in services.

2. Introduction

The Open Mind project is aimed at all people from BME (Black and Minority Ethnic) communities living in Suffolk and Norfolk. BME groups can be understood as people living in England who are designated as belonging to a non-white ethnic group (according to the national census). These include people who may be classified as seeking refuge or asylum within the country.

Engaging people who use mental health services in developing those services, a process generally known as "user involvement", has developed over the years to become part of policy (DoH 1999, 2005; NIMHE 2003). Involvement and participation initiatives are now on the agenda of most mental health trusts. That user involvement is central to changing services for the better is based on the idea that service users and survivors are experts in their own experiences and that self-organisation and self-determination are crucial in their journey to recovery.

This project particularly aims at enabling and empowering BME communities to raise any concerns regarding accessing and using mental health services. It also aims at providing an opportunity for Norfolk and Suffolk NHS Foundation Trust (NSFT) and other local organisations to listen and gain a better understanding of how mental health is perceived and affects different communities. In turn we hope to bridge some of the existing gaps that exist, create a better relationship between services and communities and to start a co-production approach when it comes to developing and reviewing services.

This project also gives professionals the opportunity to acknowledge the challenges that exist within the system itself such as when using terms or language like "hard to reach" which not only explain very little about the actual underlying problems for specific communities but are a highly problematic generalization as they can be stigmatising categories which assume homogeneity within disparate groups.

The communities that get grouped routinely under the term have been called obstinate, disadvantaged, illiterate, information poor, chronically uninformed (Freimuth and Mettger 1990), difficult, separatist, unmotivated and regressive. In the context of participation and involvement, the onus is placed on the communities identified as "hard to reach" – they are the problem – and not the ways in which involvement is defined or undertaken.

This report provides an overview of the main findings or outcomes of the workshops where members of the BME communities discussed their views and experiences.

"If you have a mental health problem in my country, the community may not want to know about you and you are 'marked' for the rest of your life."

3. Purpose and structure of workshops

Workshop purpose

- To give local BME communities an opportunity to engage and have their voice heard
- To gain a better understanding of mental ill health among our BME communities
- To explore the barriers to mental health care faced by our BME communities
- To have a better understanding of the experiences of BME service users when it comes to mental health care
- To identify potential solutions and service improvements
- To help build a positive relation between BME communities and the local NHS staff

Workshop structure

The Open Mind workshop has been a first time event organised by NSFT, Caribbean and African Community Health Support Forum (CACHSF) and Suffolk Refugee Support (SRS) in engaging with local BME communities and the intention was to pilot and test the workshop format in Suffolk to inform on future workshops or engagement events across other areas within Suffolk and Norfolk. Members of both CACHSF and SRS have been engaged from the beginning until the end in influencing and shaping the design of the workshop in ensuring a co-production approach was followed. Other representatives from local organisations also contributed in helping towards the development of this workshop, namely Healthwatch Suffolk (HWS), Norwich Mind, Suffolk Family Carers (SFC), Ipswich and East Suffolk CCG (IESCCG), West Suffolk CCG (WSCCG), Suffolk Wellbeing Service (SWS), Voiceability, Suffolk User Forum (SUF), Ipswich Hospital NHS Trust, Public health, Suffolk Constabulary, CSV media and Ipswich and Suffolk Council for Racial Equality (ISCRE).

There were two workshops which consisted of two topics each (see table 1 below). Discussions were facilitated in such a way as to encourage individuals to talk about their understanding of mental health and openly share their experiences (including both positive and those that are unstisfactory) in relation to mental health services.
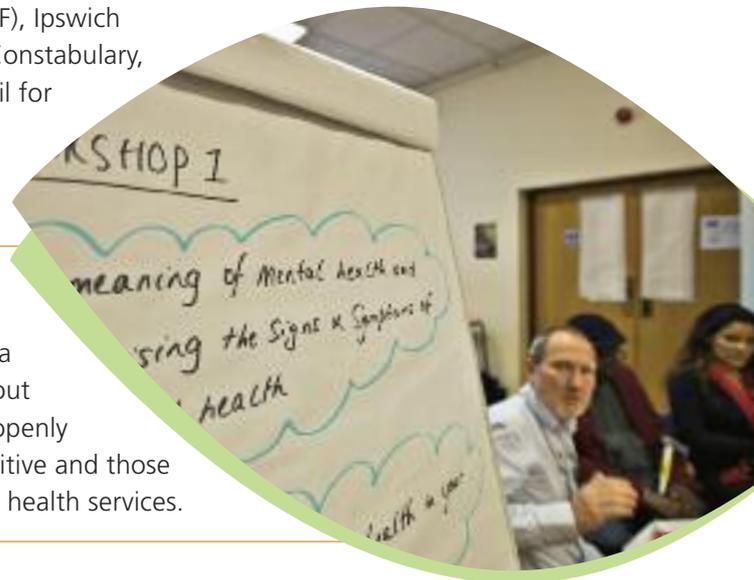
Workshop 1	
1.	What does mental health mean to you and how do you recognise the signs and symptoms of mental ill health.
2.	Coping with mental ill health.
Workshop 2	
3.	Barriers in accessing local mental health care.
4.	Experiences of using local mental health services.

Table 1

4. Participants

There were over 55 people who attended the workshops of which we had around 12 representatives from public and voluntary organisations that helped with facilitating. The BME communities that attended were very diverse, including various nationalities of African, Caribbean, Asian and middle-eastern origins. A detailed breakdown of the profile of those who attended on the day wasn't captured as most people did not complete or provide their full personal details upon registration.

Attendees were divided into five groups of 10-12 people with a balance of facilitators and people from the communities in helping them engage with the process. All four topics were discussed in each of the five groups with an allocation of one hour for each of the workshops. Notes were captured by the facilitators which were then collated to inform this report.

"..I still have lots of episodes of mood swings, sleepless nights, anxiety, and many more but yet I want to share with you how I am coping with my illness.."

5. Guest Speakers

1. Alan Bramwell
(Redesign Project Manager, Ipswich and East Suffolk CCG)

2. Evariste Kanamugire
(Member of the Suffolk Refugee Support)

3. Noel Thompson
(Member of the Caribbean and African Community Health Support Forum)

4. Robert Nesbitt
(Trust Secretary of Norfolk and Suffolk NHS Foundation Trust)

**5. Zamrooth Sherifdeen**
(Member of the Suffolk Refugee Support)

1. Meaning of mental health

There was a wide range of answers to this question. Some examples of diagnosis were discussed (depression, schizophrenia etc). This reflected understanding of the type of diagnosis offered to service users in response to seeking professional support. There were also comments made about the fact that within that diagnosis there may be a wide range of experiences (depending on circumstances). However the idea that mental distress could be linked to a "spiritual awakening" was also discussed. This reflected the idea that these experiences could be seen as either positive or negative (depending on one's innate beliefs). The idea came up that there may not actually be corresponding words (or even words at all) in a culture for particular states of mind.

Feelings such as "being out of control", "getting angry", not being able to speak to others, being introverted, having low self-esteem and being frustrated were seen as indications that someone might be unwell. Once again these experiences may not always be seen as negative, "you can learn from these experiences and move on". The voice hearing experience was mentioned as the initial symptom that leads some people to think they are unwell.
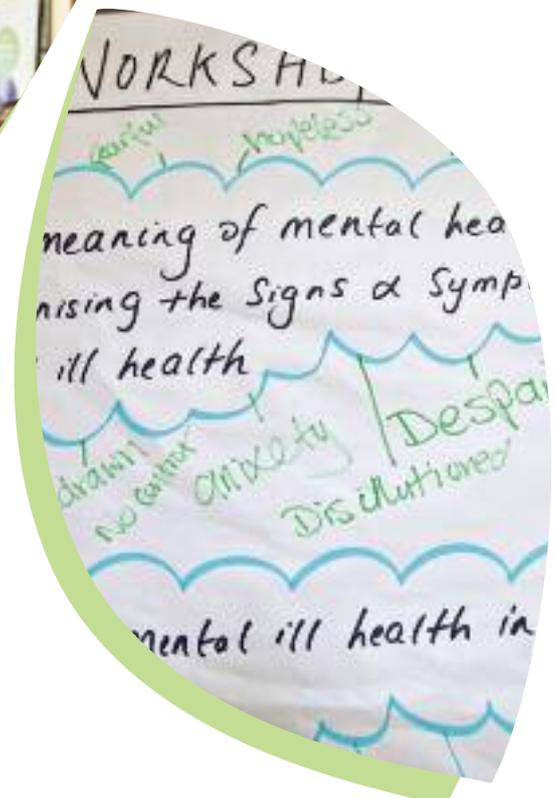
"..my depression worsened after a period of admission in the psychiatric ward as I felt imprisoned and isolated.."

2. Coping strategies

It seems other issues were addressed tangentially when asked about individual coping strategies. Individuals tended to talk about issues that were seen as barriers (see under barriers for further details) in helping them to cope such as:

• Lack of understanding about where to get support (at times)
• The fact that mental health may not be seen as so important as physical health needs in some societies was also mentioned
• Lack of appropriate support linked to other issues

Those issues included:

• Feelings of shame
• Misunderstanding or lack of empathy from professions, and also fear

Fear was particularly relevant to those people that were refugees or had immigrant status because of the more general anxiety about their status and the issues and trauma that they have faced back in their country of origin.

• There seemed to be a mixture of responses that would indicate that family could be 'protective' and supportive, but within a more general context of shame within the community

One of the guest speakers (ZS) spoke powerfully about how the use of painting has had a positive impact on her mental health, particularly as a coping strategy.

Through the medium of art she was able to express herself and communicate to others about the pain and suffering she has been going through. This has enabled her to cope with the ongoing distress and trauma that she has been experiencing as part of her mental health problem.

"The most important thing that kept me going and helps me to cope with my mental health problems are my paintings....I never knew I could paint before that time and yet my paintings filled my sleepless nights..."

3. What barriers are there to accessing services or treatment?

Feedback from this topic discussion was mainly associated with either communication or culture. It could be argued that there was a strong connection or overlap between these two themes.

- **Language / communication**

Effective Communication (in its widest sense) seemed to be a core theme in the discussions. Answering this question provoked a range of issues that demonstrated the importance of effective communication, errors that can occur when communicating, and the importance of cultural awareness in interpreting behaviour within a cultural context. For instance it was pointed out that some people use more demonstrable body language which can be seen as threatening by those that don't understand it is "normal" behaviour. This can have dramatic consequences with regards to the interpretation by professionals assessing mental health state and also the potential risk from the service user. Even where there is a common language the implied meaning of particular words may be quite different for those involved, depending on their cultural background. Accents that may be harder to understand can in themselves be a potential barrier (especially where professionals are short of time). The importance of having appropriate and qualified interpreters available at the time when it's needed was highlighted.

There were also many comments that professionals seemed disinterested in listening to them or their carers. It was acknowledged that professionals are busy people, but the language barrier or lack of knowledge about cultural background was an added feature that was perceived to make professionals less inclined to bother. All this at a time when people don't feel they can deal with being rushed, don't feel confident to ask questions and where trust might already be quite low towards those offering a service. Situations could develop where "not understanding" is then interpreted by professionals as the person being "non co-operative".

• Cultural understanding and competence

Another barrier seems to present itself as gaps in the professionals' understanding about what is acceptable to discuss or not to discuss in particular circumstances.

An example was the fact that professionals often ask about whether someone is having thoughts about suicide.

In some cultures this is a really shocking thing to be asked and (unless handed sensitively) could cause an immediate problem in developing a therapeutic relationship. The concept of a carer's assessment and home treatment came up. Where there are ingrained cultural expectations of the family "caring for" someone, the idea of having support for the carer is very much welcomed. However, that may raise some issues about the nature of the professional / carer relationship especially where that person is being treated (and supported) within the family home rather than in hospital.

The difference in the beliefs held (spirituality versus medicine to be simplistic) may cause difficulties and barriers to mutual understanding and agreement about planning care. For example GPs were seen to both lack knowledge, and were too keen to "write out a prescription" rather than discussing and investigating the problems that were presented. Once again a high level of trust was being demanded in simply accepting the professionals' response without any dialogue taking place.

• Fear

As previously alluded to, there is another barrier to seeking support which is that of fear. That might be seen as a general anxiety relating to some of the cultural issues discussed, or more pointedly related to the status of those seeking support. Refugees and potential émigrés could be particularly anxious and fearful of authority, and the potential consequences with regards to their status in the country. This understandable (yet problematic) anxiety could also contribute to someone's failing mental health and therefore create a serious problem in terms of finding the appropriate support.

"..not knowing whether I would see my family again, my mental health became worse and to add to the distress I did not know what to do and where to go for help.."

- **Lack of trust**

This highlights one of the core issues discussed during the day which is the importance of developing trust in those offering professional support. This appears to be a complex area to discuss, with many factors that would enhance or detract from a trusting relationship.

- **Lack of information and support**

There were also many comments about the lack of information available, or people not understanding how to find out information about services. Some people referred to the fact that they only found out by chance about particular types of professional support that might be available. Questions asked in the workshops highlighted the paucity of information that many people felt there was to let them know who to contact or what may be available in terms of support.

4. What are your experiences of using mental health services?

- **Racism / discrimination**

There was some discussion about incidents that were deemed to be overt racism. However, that was seen alongside some of the wider issues of discrimination (barriers to services) that people from a BME background may experience. The lack of understanding, the obvious lack of training of staff (both from primary and secondary care) was spoken about. Environment was also an issue, because if someone is taken out of their community that environment may be a key contributing factor in making a person's mental health much worse. That may due to be the perceived lack of understanding, or the knowledge of staff, which is seen as "uncaring". This often leads to an individual's needs not being meet (diet, cultural, spiritual needs etc) and that increases stress that affects their overall mental health state.

The perception was that the current mental health "system" appeared to make more demands for people to "fit in" with the needs of the organisation, rather than professionals having to adjust to the needs of individuals. It was felt that (where professionals came from a "narrow" range of society) staff did not feel confident and competent in understanding or addressing the needs for people outside of their own experience. So, in effect people from BME backgrounds may feel discriminated against through that lack of understanding (or empathy) needed to address their particular needs. There were comments such as "you need to tailor services around the needs of patients", "do not fit in as a person of colour" and "we don't fit in" which were examples of the feelings expressed in the workshops.

Workshop 2

Victimisation and discrimination was also experienced on the ward due to a lack of understanding and ignorance of cultural differences between BME and non-BME individuals. Individuals from a BME background felt that they were more likely to experience control and coercion due to the level of incompetency and attitudes of certain staff. An example was given by one of the attendees (NT) where he experienced an incident of racial abuse and bullying behavior from another patient and yet when he confronted the person who was abusing him, he was the one that was physically restrained by staff which in effect made him feel that he was the "bad person". This particular incident is an example where some BME patient may become more vulnerable which may lead to the "circles of fear" and "circuits of control".

"..I was treated and judged by staff as the perpetrator and not the victim after being bullied by a fellow patient and for that I was the one that was physically restrained which made me feel more vulnerable.."

7. Findings

There were four key issues that were identified from the findings. "Cultural awareness and competence" has been added to the list as a separate issue because there was a clear indication that this has been a strong contributing factor in acting as a barrier to accessing services, building a positive therapeutic relationship with professionals, trusting services when they need it as well as having a positive experience when using services. Those four categories are classified as below:

- Accessing services
- Availability of information
- Cultural sensitivity, awareness, understanding and competence among staff and services
- Lack of trust

Accessing services

The first contact for most people in accessing mental health services is usually the GP surgery and yet it was clear that issues such as cultural awareness cropped up as a barrier for many in getting the right support and treatment. Some people mentioned how uncomfortable they felt about telling the receptionist why they needed to see their GP which in itself often can be a barrier. Other barriers within the GP surgery included things such as time constraints and language barriers, where communication and cultural differences may demand more time to properly assess the need of the individuals and their carer. The lack of quality of the assessment may therefore be compromised and individuals are not getting the services or support they need. A lot of people did not even know they could book a double appointment and therefore they were not able to get the time they needed with their GP.

There were also concerns raised that GPs sometimes themselves did not know or understand the range of services that were available and that they only had a general level of knowledge or understanding rather than being seen as an expert.

It seemed to be felt that as the GP surgery was the gateway to further support and services, primary care has a responsibility to respond to the needs of the BME communities or at least have a more supportive and easily accessible service within the environment they felt comfortable they can use when the need arises.

There was yet another dimension regarding access to services for refugees and those seeking asylum. It was obvious that people can often be reluctant to disclose / discuss issues about themselves with people in authority due to their formative experience. Many asylum seekers as described by one of our speakers have suffered torture by authorities in their country and furthermore negative attitudes and experiences from mental health service interventions as well as from some people in the society in UK. It was clear that those people already anxious about their rights to stay in the UK would then be reluctant to seek help.

Overcoming any misplaced fears about seeking medical assistance many need to be a pre-cursor to actually attend a medical assessment and needs to be seen as an issue in its own right. How the person is responded to at any initial contact is going to determine the nature of future relationships for better or worse.

Availability of information

There was no doubt that gaining access to information about what service is available, or the rights of individuals to mental health support was a big issue for many. Where the individual has overcome any barriers at the primary care level (and subsequently entered secondary care), access to information about the way services operates is necessary. This is a general point that can be applied to the rights of all service users, but it is important to bear in mind the opportunities for misunderstandings due to cultural or language differences are much wider among BME communities.

Having an understanding of what choices and rights you have and wider understanding about the potential outcomes is crucial to the reduction of stress or anxiety. To avoid unnecessary stress or anxiety professionals should not make any assumptions about the level of understanding a service user or family carer might have and therefore it is vital that they take the time to explain the process and options available to individuals.

Having an understanding of what choices and rights you have and wider understanding about the potential outcomes is crucial to the reduction of stress or anxiety. To avoid unnecessary stress or anxiety professionals should not make any assumptions about the level of understanding a service user or family carer might have and therefore it is vital that they take the time to explain the process and options available to individuals.

Cultural sensitivity, awareness, understanding and competence among staff and services

The attitudes of professionals were a core issue for discussion. The perception was that for BME service users and carers the added complication of language and other cultural differences and misunderstandings created a divide between them and professionals and for some were seen as barriers in accessing services that were not culturally sensitive to the needs of the BME community as a whole.

Trust was greatly reduced in circumstances where it was obvious that the professional either had no understanding or more importantly where they demonstrated little interest in discussing aspects that were very important to the person. There were incidents where individuals suffered overt racism and other times where incidents involved professionals showing a lack of interest or ignorance that led the individual to believe that it was their BME background that was the issue. This meant for some that they did not get the service they needed as they felt they "did not fit in".

Placing language issues themselves to one side, it was the opportunities for (mis)interpretation of aspects of speech and behaviour (for those from a BME) background that was a source of frustration. Such misunderstandings can have serious consequences for the individual concerned. Personal attributes that demonstrated the desire to communicate well and to attempt to understand better the importance of service user needs were given a high priority. Where professionals exhibited these qualities relationships improved and trust was developed.

Trust

It was very clear that lack of trust in the professional offering services was a big issue for many people. Whilst the person's culture was seen as an issue in itself, the commonality in the discussions was the need to feel that practitioners actually demonstrated warmth and caring. Regardless of the person's culture the necessity of being listened to and helping the individual articulate their needs was seen as crucial

Good communication, willingness to understand, offering appropriate information, offering time to discuss (particularly during language and cultural barriers) were all seen as qualities that were both desired and expected from professionals in order to develop a trusting relationship (that is the prerequisite for a therapeutic relationship) which means both service user and professional working together in addressing the problems.

8. Discussions

So there appeared to be many barriers and frustrations experienced from the first consultation with the GP right through to the care delivered by the secondary care services. Many comments (already spoken about) related to attitudes and values, alongside the frustration of not understanding the way the "system works: or getting timely or appropriate information regarding the potential support that may be available. When support was available there seemed to be many experiences of misunderstanding or a feeling that they were not being heard in terms of their needs or their own values being taken into account.

"..none of the staff seemed to understand or at least show the willingness to understand my culture and yet this is an important part of my life."

It is very important to state that although the focus of the workshops was to encourage people to discuss issues such as the barriers to effective services we did indeed have positive feedback from service users and carers about some of their experiences within the mental health services. Put simply, those "good experiences" seem directly related to skills of particular professionals (and other members of staff) in terms of their sensitivity to many of the issues and pitfalls discussed within this report. The difference between positive or more negative experiences may be due to the level of cultural awareness, understanding and competence they had attained through training and / or the intrinsic values of the practitioners. However (in general) the workshops highlighted a wide gap between the expectations and the reality of what BME service users and carers experienced as well as those who need a service but feel a lack of support in accessing services.

9. Recommendations

From the findings gathered it seems that the issues raised could be divided into the following:

a. Those that will affect all service users irrespective of their background or ethnicity (not specifically related to the BME community)

b. Those issues that are specific to (or exacerbated by) being part of a BME group

These findings should provide health care commissioners as well as providers with a very useful and powerful message that will help us all to deliver a better service to our diverse communities.

Therefore our recommendations are as follows:

• **To improve access to information about services and access to translated materials when needed**

• **Better communication through access to interpreters and sufficient time given to allow for a comprehensive assessment of needs**

• **To improve cultural competence skills amongst staff**

• **To improve cultural capability within organisations**

• **To develop and implement a co-production approach between services and BME service users**

• **To improve choice and availability in service provision for BME communities**

• **To increase the involvement of BME service users by developing a BME service user forum**

"I needed people to hang around and it was important for me to feel connected with a group of people I could do meaningful activities together and also at the same time know that I can be supported during difficult times."

10. Sharing the Open Mind Dialogue workshop Outcomes

The intention and purpose of carrying out this project is to seek opportunities to share the outcomes from this Open Mind workshop widely firstly within NSFT as the main provider of mental health in Suffolk and Norfolk but importantly also with all local stakeholders that have a key role in commissioning or improving the quality and equality of health care for the local communities.

Our initial contact will be with key individuals from the following organisations:

- Anglo Chinese Cultural Exchange
- Bangladeshi Support Centre
- Caribbean and African Community Health Support Forum (CACHSF)
- CSV Media
- Eastern region BME Network
- Healthwatch Suffolk
- Healthwatch Norfolk
- Intran
- Ipswich Hospital NHS Trust
- Ipswich and East Suffolk Clinical Commissioning Group (IESCCG)
- Joint Diversity working group
- Norwich Mind
- Public Health Suffolk
- Suffolk County Council

- Suffolk Family Carers
- Suffolk Refugee Support
- Suffolk Constabulary
- Suffolk User Forum
- Suffolk LGBT advisory Network Group
- Suffolk Mind
- Voiceability and Suffolk wellbeing service
- West Suffolk Clinical Commissioning Group (WSCCG)

We would be grateful for further suggestions. So anyone wishing to add to this list should contact Ravi Seenan by email: ravi.seenan@nsft.nhs.uk

11. Acknowledgements

On behalf of NSFT, CACHSF and SRS, we wish to express our sincere gratitude to everyone that attended and participated in the Open Mind workshop specially our speakers (Zamrooth Shefideen, Noel Thompson and Evariste Kanamugire) and also all the facilitators for their huge contributions and support in making this workshop a positive, engaging and informative event.

We also thank Michael Clarke for his presentation through the powerful use of drama, Russel Clarke and John Fergusson for taking photographs of the event, Sandra Jones for keeping us entertained with her saxophone and Clem Turner for his support in helping us to organise the event.

Our gratitude also goes to Derek Jones from Suffolk User Forum in his commitment, passion and time he spent in helping us writing this report.

Norfolk and Suffolk NHS Foundation Trust values and celebrates the diversity of all the communities we serve. We are fully committed to ensuring that all people have equality of opportunity to access our service, irrespective of their age, gender, ethnicity, race, disability, religion or belief, sexual orientation, marital or civil partnership or social & economic status.

Suffolk Family Carers
Living Fuller Lives

healthwatch Suffolk

SUF
Suffolk User Forum

The Ipswich Hospital NHS
NHS Trust

VoiceAbility