

Diversity and Inclusiveness in Dementia: Listening Event Report

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Diversity and Inclusiveness in Dementia

Listening Event Report

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ABSTRACT

This report provides feedback from a Listening Event held in Salford on March 10th, 2014 which explored issues in relation to diversity and inclusiveness and dementia and captured the views of professionals, service providers and people living in the Salford area. The aim of the event was to learn from and with people from different communities how we (Salford Institute for Dementia, Greater Manchester West Mental Health Foundation Trust, Alzheimer's Society and other partner organisations) can meet the needs of people with dementia in a way that responds to diversity by promoting inclusivity.

Background

There are currently 25,000 people with dementia from BME communities in England and Wales and this figure is expected to grow to 50,000 by 2026 and 172,000 by 2051 (All-Party Parliamentary Group on Dementia, 2013). Dementia has been identified as the biggest health and social care challenge facing society and disproportionately people from BME communities are being failed by the system (All-Party Parliamentary Group on Dementia, 2013). The available literature indicates that there is a need to gather more information and engage with BME communities for practical reasons: to implement preventative measures particularly around modifiable risk factors and early diagnosis; to raise awareness among health and social care staff and BME communities; to improve information and dissemination about dementia services; to gather more knowledge about the role of carers in BME communities and to debunk stereotypes; to capture the diversity in and among BME communities; to identify priorities for workforce training; and to gather intelligence about the appropriateness of generic or culturally specific dementia services (Moriarty et al., 2011).

Approach

The Listening Event brought together a range of people with an interest in or direct experience of dementia. Attendees included people living in Salford from a range of communities, professionals, service providers, carers, representatives from organisations working with people who are living with dementia and academic staff from diverse backgrounds with an interest and expertise in dementia

Findings and Discussion

The findings and topics points raised at the Listening Event can be summarised as follows:

- BME and less heard communities may not recognise the term dementia
- Participants suggested that diverse communities are not hard to reach, instead they are easy to ignore
- It is important to acknowledge that many of the barriers affecting people from BME and deaf communities also affect the general population
- Communication is an issue: people do not know who to contact to get help
- There are issues around trust and fear of approaching GPs and other professionals
- People may feel overwhelmed by the number of agencies that need to be dealt with
- People may not always recognise that they are a carer and many people are not registered as carers by their GP
- Services are Eurocentric and there is often a lack of knowledge among professionals of different cultures
- There may be greater reluctance to come forward in some cultures, but we should not make stereotypical assumptions about BME groups always caring for family members
- There is a stigma surrounding diagnosis. Many people were worried about getting negative perceptions from professionals.
- People from diverse backgrounds are not represented in local authorities and services
- There is limited dialogue between minority communities and service
- It was also widely accepted that cuts to spending on services has made this situation worse

Conclusions

There was a strong commitment among participants to improving access to services and increasing awareness of dementia among less heard communities. However, it was acknowledged that more work needs to be done in Salford to identify the needs of diverse communities and what is understood by the term “dementia” and in order to facilitate this, more joined up working between service providers is necessary.

FOREWORDS

Professor Lord Patel of Bradford OBE

In the UK we have a large and diverse Black and Minority Ethnic (BME) population which is now reaching old age. Projections suggest that as this population ages, the number of BME people living with dementia will increase. Although dementia is a challenge facing society as a whole, an All Party Parliamentary Group report , *Dementia does not discriminate: the experiences of black, Asian and minority ethnic communities* 2013) suggests that people from BME and less heard communities are not receiving appropriate care and support. There is still very little known about diverse communities and dementia and the work of the Institute of Dementia at the University of Salford is playing a key part in beginning to fill some of these important gaps in knowledge.

Professor Maggie Pearson Pro Vice Chancellor Public Benefit and Dean, College of Health & Social Care

Although colleagues from black and minority ethnic communities have been crucial to the establishment and survival of the NHS, since its inception in 1948, the service has been ironically slow to acknowledge, understand and respond to their needs. Successive reports since the late 1970s have highlighted the lack of responsiveness of health and social care services to minority communities' experiences. This report of a Listening Event held in Salford in March 2014 shows that dementia is no exception. Participants clearly felt that their experiences and interpretation of what we term 'dementia' is not understood by the services currently provided. The Salford Institute for Dementia will take this work forward to develop a more robust evidence base, but the clear messages from this Listening Event provide an agenda for health and social care services, no matter whether in the public, private or third sector.

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1 INTRODUCTION

The term diversity is a relatively new way of dealing with equality and goes beyond legal compliance with the Equality Act 2010. Instead, it captures a range of people, groups and communities and focuses on inclusion. In March 2014, the Institute for Dementia at the University of Salford undertook a listening event to identify the issues regarding diversity and inclusiveness in dementia. This fits with the research and practice priorities of the Institute and builds on previous engagement events with community members and professionals. The aim of the event was to learn from and with people from diverse communities. However, we recognised that as we are still at the stage where we are learning how to connect with people from diverse communities regarding dementia, we were likely to have fewer 'people' and stronger representation from practitioners and professionals. When carrying out the group discussion we ensured that the voices of people from different communities were heard as a priority.

Participants included professionals working in health and social care, social services, the voluntary sector, academics, community members, some of whom identified as carers for people living with dementia. There were 47 attendees in total, including facilitators. This report brings together the finds from the listening event and highlights key issues raised in the literature on minority groups and dementia. We highlight gaps in current research and identify future research priorities in this area. The report is structured as follows: in the next section an overview of diversity and inclusiveness in dementia is presented followed by an outline of the Listening Event approach. We then present the findings from the discussions and activities at the event and highlight the issues facing less heard communities regarding dementia. We suggest ways to ensure that people from marginalised communities access service and highlight possible next steps.

2 Diversity and inclusiveness in dementia: overview

Migratory patterns since the 1950s mean that the UK is now home to a significant and diverse Black and Minority Ethnic (BME) or Black Asian and Minority Ethnic (BAME)ⁱ population which is now reaching old age. On census day 2011, there were 1.25 million people aged 85 or over living in England and Wales, compared to 1.01 million in 2001 (ONS, 2013a). In 2011 13% (7.5 million) of the resident population of England and Wales were born outside the UK compared to 4.3% (1.9 million) in 1951, indicating that migration has contributed to 45% of the total population change over the last 60 years (ONS, 2013b).

It is projected that by 2051 the BME (including white ethnic minority groups) population in the UK will have reached 25 million, making it 36% of the total. Projected figures for the size of the non-white population by 2051 are 20 million, or 29.7% of the total population. Estimates indicate that by 2051 there will be 3.8 million BME older people aged 65 and older, and 2.8 million aged 70 and older. In terms of the BME population, projections suggest that by 2051 there will be 2.7 million people aged 65 and over, and 1.9 million aged 70 and over (Lievesley, 2010). These projected figures indicate that demand for welfare services for older people will increase and that a significant proportion of this demand will come from BME populations. The number of people with dementia from BME groups in the UK is increasing as people are getting older (All-Party Parliamentary Group on Dementia, 2013), and, this increase in the number of older BME people with dementia will inevitably lead to an increase in the need for dementia services (Moriarty, J. Sharif, N. and Robinson, J., 2011).

It is estimated that there are currently 25,000 people with dementia from BME communities in England and Wales and this figure is expected to grow to 50,000 by 2026 and 172,000 by 2051 (All-Party Parliamentary Group on Dementia, 2013). Dementia has been identified as the biggest health and social care challenge facing society and disproportionately people from BME communities are being failed by the system (All-Party Parliamentary Group on Dementia, 2013). The National Dementia Strategy emphasises that health and social care staff should take account of the needs of BME people, however, service providers have reported challenges in including people from BME communities (Williamson, 2012), and this is compounded by a lack of BME

representation among health care professionals (Catalyst, 2014). Among BME communities there are lower levels of awareness about dementia and high levels of stigma surround the disease (Moriarty et al., 2011). BME people are underrepresented in dementia services, and there is also evidence that BME people with dementia present late to services (APPG, 2013). Indeed, although there are no reliable figures available it is likely that dementia is more common among BME communities since the (modifiable) risk factors: high blood pressure, diabetes, hypertension and high cholesterol are more common (APPG, 2013). Vascular dementia is also believed to be more prevalent among BME population because they are more prone to such risk factors (Moriarty et al., 2011).

It should be noted that the evidence base on BME communities with dementia and their carers is very limited, and there is a paucity of research. However, the following themes appear to recur (Moriarty et al., 2011):

- BME people living with dementia and their carers face difficulty in accessing services and often access services later
- In many BME communities there is no word for dementia which makes framing and describing the disease difficult
- There is an inability to exercise choice in care and support services because of lower levels of awareness about dementia and higher levels of stigma among some communities
- Different communities have different expectations about care and service providers have often stereotyped BME communities in terms of 'they look after their own'
- Services are generally not culturally appropriate

The available literature indicates that there is a need to gather more information and engage with BME communities for practical reasons: to implement preventative measures particularly around modifiable risk factors and early diagnosis; to raise awareness among health and social care staff and BME communities; to improve information and dissemination about dementia services; to gather more knowledge about the role of carers in BME communities and to debunk stereotypes; to capture the diversity in and among BME communities; to identify priorities for workforce training; and to gather intelligence about the appropriateness of generic or culturally specific dementia services (Moriarty et al., 2011). There are a number of implications arising

from this, for policy, commissioning, and practice and also from the perspective of service users and carers, as follows (Moriarty et al., 2011):

Policy implications

- Involve BME (and other minority) communities in decision making about service development
- Information dissemination and communication strategies are needed

Commissioning implications

- Increased number of BME likely to need dementia services
- Consultation needed
- A range of method of providing care and support need to be explored

Practitioner implications

- Impact of stigma and cultural expectations
- Information dissemination
- Avoiding stereotyping

Service user/carer implications

- Support needed
- Early intervention needs encouraging

From the available literature it seems clear that awareness-raising to improve access to services should be prioritised since BME communities currently have very poor access to diagnosis and support. However, there is also a need for targeted preventative work and to tackle modifiable risk factors. Further key priorities should be improving staff knowledge, skills and delivering culturally appropriate services (APPG, 2013). These priorities would need to be informed by evidence gathering: currently there are gaps in research in relation to how BME people experience the process of assessment and

review; service preferences and what 'culturally appropriate services' would look like (Moriarty et al., 2011).

Finally, it should be acknowledged that although it is inequitable not to take account of the needs of BME people and other minority communities with dementia, to overlay the differences from the indigenous population and 'problematize' their needs also creates difficulties and can lead to exclusion (White, 2007). In other words, not planning for the specific needs of BME communities with dementia can lead to their marginalisation but narrowly focusing on the distinctiveness of their needs can also create exclusion.

3 THE LISTENING EVENT APPROACH

The half day event was designed to elicit the views and experiences of participants in relation to dementia. The activities (see appendix 1 for an overview of the day) aimed to prompt a discussion of the issues around diversity and inclusiveness. Participants were split into groups and each group was seated around a table with two facilitators. One facilitator chaired the group discussion while the other acted as note-taker. Although the listening event cannot be classified as 'research' per se, it did allow us to gather information about a range of experiences and perspectives from participants. In total 47 people attended the event including facilitators and note-takers. The majority of attendees were from Salford, and there was also representation from Manchester and Rochdale.

Professionals and practitioners from a range of health and social care organisations were the majority in attendance and there was representation from minority ethnic groups and carers among these attendees. In addition, a number of people from minority ethnic communities who live in Salford attended and there was also representation from the deaf community. We did not group people on each table in any particular way; instead participants chose where to sit. We felt that it would be difficult to meaningfully categorise people since categories overlapped. Our main aim was to ensure that everybody had the opportunity to participate and that we would be able to gather information from a range of perspectives.

3.1 Discussion 1: Understandings of 'dementia'

In the first discussion participants were asked to say what they understood by dementia and cards with the word 'dementia' were placed on each table. It should be noted that participants at this event had high levels of knowledge and awareness of dementia since many were employed by organisations involved in dementia-related services and several attendees were also carers for people with dementia. Participants highlighted that the term 'dementia' captured a range of different illnesses denoting disease of the brain including; Alzheimer's Disease, Picks Disease, Vascular Dementia and that dementia could be caused by strokes, high blood pressure, hypertension, high cholesterol and diabetes. Attendees also highlighted that dementia is not a natural part of ageing but that ageing is a risk factor, although younger people can also develop dementia. However, participants acknowledged that in society as a whole, awareness and understanding of dementia was often limited and that there is confusion regarding the difference between Alzheimer's and dementia. There are also many misconceptions of dementia and a lot of fear with little knowledge. Participants acknowledged that everybody's condition and experience of dementia is different and that understanding of the person is very important. Another issue raised was the stigma surrounding dementia – for all communities – often dementia is seen as a derogatory terms and there is a lot of negativity associated with it, although it was considered important to remember that it is possible to live well with dementia.

3.2 Discussion 2: 'Your community' and understandings of dementia

It should be noted that when we designed the listening event we anticipated the majority attendance to be people from BME communities in Salford. As the event approached however it became apparent that professionals working in the area would outnumber community members. We thought this was interesting since it clearly indicated a need among health and social care practitioners to learn more about the needs of the BME population. We were careful to ensure that people could define how they saw their 'community' throughout this exercise. Some people identified on the basis of ethnic group, while others identified as carers, professionals and some as a combination of all three categories. Discussions among the groups highlighted a number of issues which will be summarised under the following headings: stigma; language of dementia; lack of awareness

and understanding of dementia; cultural responses to caring; and overview of group feedback.

3.2.1 Stigma

A number of participants mentioned stigma in relation to dementia in BME communities. It was suggested that among Punjabi, Gujarati and Chinese communities that dementia was a 'taboo' subject. Dementia is also considered taboo within certain African countries, for example Nigeria, Cameroon and Central African Republic. This results in people being stigmatised, segregated and socially isolated and families often distance themselves from the person with dementia by hiding them or abandoning them through fear of rejection from the wider community. In these cultures it is thought that when an individual develops dementia that it indicates that there is something wrong with the whole family, preventing engagements and marriages. It was also highlighted that culturally there is stigma and embarrassment surrounding dementia in South Asian countries due to the way that asylums and institutions have operated there. It was also felt by some that some references to mental health in religious texts fuel stigma and create barriers to people accessing services. In some communities poor mental health is associated with sin and people can believe that they are being punished in some way. This is complicated and difficult to overcome, but means that people feel guilty about their illness so do not access support.

3.2.2 Language of dementia

In some BME communities there is no word for 'dementia', instead, words used to describe dementia are 'crazy' and 'mad' which is not helpful in removing the stigma surrounding dementia or encouraging people to come forward and seek support.

3.2.3 Lack of awareness and understanding of dementia

Some participants who identified themselves as BME indicated that among their communities there was a lack of awareness and understanding of dementia, although others felt that awareness was increasing due to longer life expectancy and increased prevalence of the disease.

3.2.4 Cultural responses to caring

There appeared to be conflicting information given on this subject which in itself highlights the contested notion of there being a definitive cultural response to dementia care. Some participants suggested that the family would automatically care for someone living with dementia, while others questioned whether the stereotype surrounding BME communities and care for family members still applied to younger generations. It was also suggested that carers themselves are becoming older and need support. The key message from this aspect of the discussion is that we should not make assumptions, that everybody's experience is different and that this should be taken into account.

3.2.5 Overview of group feedback

At the end of this discussion groups were asked to select one comment that they felt to be the most important and a summary of these is presented below:

- Everyone is an individual and we cannot make assumptions about groups and communities
- There is a need for the public to be aware of issues and processes involved in dementia. There needs to be an integrated approach in the provision of services, ideally an "all inclusive" service where people can be signposted in the right direction
- More information needed on where people in the community are living
- It is important to recognise that it is not just the individual but the whole family also needs support since they may not know about dementia or what the next steps are.
- Work needs to be done to shift the negative connotations surrounding dementia. Positive awareness should be promoted in a range of languages.
- More awareness about dementia needed and more needs to be done to raise awareness. More detail and more information need to be made available.
- Communication and information strategies are needed.

3.3 Discussion 3 – ‘J’ and family

Each group of participants were given a case study as a basis for discussion. A facilitator from each table read out the case study and each group addressed a number of questions centring on the important issues in the situation, responses and support needs. The purpose of the case study was to highlight the complexities surrounding dementia, caring and family dynamics. We deliberately made J’s gender and ethnicity ambiguous, but this case study was actually based on a real-life situation where J was in fact male and of Pakistani origin.

3.3.1 The case study

J is 18 years old and attends Sixth Form College and hopes to go away to university next year. J lives with both parents and a younger sister, aged 13. One of J’s parents is disabled and J’s other parent is the carer. Recently J has noticed that the caring parent has been ‘under the weather’ and very irritable, often becoming angry at relatively minor issues. At first J put this down to tiredness due to their caring responsibilities, but some troubling instances have occurred, including forgetting to prepare meals and attend hospital appointments. J became extremely concerned on arriving home to find the sister locked out of the house, the disabled parent locked in the house, and was unable to locate the caring parent. The caring parent was later brought home by a neighbour who found them in a confused state walking in the local park. J doesn’t know what to do about the family’s problems and it is now taking a toll on J as hopes to go to university and the well-being of the family are in jeopardy.

3.3.2 Important issues in this situation

Participants were asked to identify the important issues facing J and family and these can be summarised as follows:

- There is a need for support for the caring parent, the disabled parent, J and the younger sister: all family members in different ways need support
- A holistic approach is needed for the whole family: J needs to be supported to go to university, the caring parent needs to be assessed; the disabled parent’s needs should be revisited and any support needs of the younger sister should be addressed

- It is unlikely that the family know where to go for help or how to access help
- This is now at crisis point and urgent help is required
- It seems that there is a lack of understanding of the situation and J seems to now be in the position of responsibility – it could be too much
- There could be fear about making the situation known to social care organisations. Stigma could be an issue
- There are concerns about the safety of the whole family and the impacts on all members
- J is only 18
- We cannot make assumptions about who will care

3.3.3 Appropriate courses of action

Participants were asked about what they would do if someone in their family was experiencing the problems outlined. An issue raised in all of the groups was that all families are different and we should not assume that family members would be able to offer support. It was suggested that in the first instance we should not assume that dementia was the cause of these difficulties as other illnesses could cause confusion. It was considered crucial to see a GP at the earliest opportunity and to find out about available resources.

3.3.4 The family's support needs

It was agreed that each person in this scenario has unmet needs and that these need to be properly examined.

- The disabled parent's care is compromised due to the poor health of the caring parent. A social care assessment needs to be carried out.
- The caring parent also needs an assessment to ensure that their health and support needs are properly met.
- J can also be classified as a young carer. He needs support if he is to continue his education. J needs to be encouraged to engage with welfare services at Sixth Form College.
- The younger sister's also perhaps needs support with schooling.

- It would be useful to know about the wider family and support network who may be able to help

3.3.5 What would happen if someone in your community had these problems?

Attendees were asked about what would happen in 'their community' if someone was experiencing difficulties such as these. We acknowledged that people felt themselves to belong to multiple communities. It needs to be recognised however, that the participants at the Listening Event had a good deal of knowledge about dementia and related services so their responses would not necessarily be typical. A number of suggestions were put forward and some element of good practice identified in Rochdale, where MIND has a link worker undertaking targeted work with BME communities. In Salford, reference was made to the 'Ten Steps Pathway' where processes and procedures for dementia diagnosis are outlined. However, it was acknowledged by participants that knowledge of services was likely to be limited, particularly among minority communities so the solutions presented were based on what *should* happen, rather than what might actually occur. It was agreed that 'in an ideal world', the following steps should be taken:

- Recognise a problem and be signposted or make appointment with GP
- Visit GP and get referral
- Diagnostic assessment at the memory clinic
- Diagnosis
- Treatment and support put into place
- Accesses community services (including the voluntary sector)
- Carers to access support
- Link in with Dementia Action Alliance and Dementia Friends

3.3.6 Group feedback from the case study

During the plenary session feedback was gathered from all of the groups and can be summarised as follows:

- Dementia is not a word in some communities which can make identifying the disease difficult.

- There is a need to publicise dementia services, for example in public places, for example, churches, mosques and community centres.
- In some communities there may be different expectations of girls and boys in relation to providing care. We must ensure that we do not stereotype or make assumptions that BME communities do not want care support. It was acknowledged however, that it may be more likely that in this situation a female would be obliged to stay and care for family instead of choosing to go to university.
- It is important that J is not isolated and that he receives the right support.
- Appropriate support for each member of the family needs to be assessed and delivered. Who would they contact? If a single point, they should be directed to the right person. The safety of all family members also needs to be taken into account.
- It is necessary to publicise dementia and dementia services.
- Importantly, this crisis stage should be avoided wherever possible. It was acknowledged that many people living with dementia do not receive help and support until the crisis stage so more work needs to be done to prevent this.

4 Issues facing BME communities regarding dementia

Throughout the course of the Listening Event, via the discussion points and activities a number of key themes were raised by participants in relation to the key issue facing BME communities in relation to dementia and related services. The points raised were from professional, carer, community perspectives, and often from all three since roles overlapped. Attendees commented that the issues are different for different people with dementia and this cuts across both the indigenous and BME population: in other words, in terms of services a 'one fits all' approach was considered inappropriate. It was suggested that often people were not given the correct advice about how to access dementia services and there was a good deal of concern expressed by professionals on the low numbers of BME community members accessing their services. Concern also centred on carers and whether or not they received adequate support, and again the issue not making cultural assumptions about BME communities was emphasised.

A central concern was the lack of appropriate communication mechanisms, between professionals and organisations and also between organisations and the public. This was

seen as an area where a good deal of work needed to be done to improve relationships, build up trust and encourage take-up of services. There was a view that there is a lack of understanding surrounding dementia amongst the public and professionals and examples were given from Rochdale and Salford.

- **Rochdale** - GPs not as pro-active in referring people for assessment and recognising the signs and symptoms of dementia as they could be. This has made it difficult in some cases to gain a diagnosis which prevents early treatment and planning and without which the individual and carers cannot access the support that they need.
- **Salford** - People make the assumption that dementia means Alzheimer's when there are other types, like vascular.
- **Salford** – Hospital staff can mistake delirium and psychosis caused by physical or mental illness in older people for dementia. There are lots of things that can cause confusion (e.g. urinary tract infections and dehydration).

4.1 Barriers to people from diverse backgrounds accessing dementia services

It was widely acknowledged accessing dementia services is often problematic. However, participants at the event suggested that people from diverse backgrounds experience further difficulties in relation to accessing dementia services. The needs of people with dementia are not always recognised by services because people with can underplay their difficulties as well as not always recognising the symptoms of dementia. Further, there is lack of information about BME and other marginalised communities which makes early diagnosis and interventions difficult. Participants suggested that although 'Dementia Friendly Communities' is positive, there are doubts about whether it is reaching everyone. It was also felt that services tend to be process orientated rather than person-centred which can create further barriers to access. The barriers facing people from diverse backgrounds can be summarised under the following themes:

4.1.2 *Distrust of and unfamiliarity with services*

It was felt that BME communities were more reluctant to come forward, partly due to not knowing 'how the system works' but also because of a lack of trust and concerns about what might happen if interventions take place. Concerns were expressed around BME people with dementia and their families becoming isolated and their situations becoming

more difficult through not accessing services. This could happen through the disease progressing more rapidly without treatment and increased pressure being placed on carers and family members.

4.1.3 Difficulties in gaining GP referrals

Participants discussed the logistics of gaining a diagnosis of dementia and having access to appropriate treatment and support. A recurring issue was the GP as gatekeeper: in order to have an assessment at the memory clinic and a diagnosis, a GP referral is needed and there were a number of examples given where GPs failed to recognise dementia. This was widely felt to be problematic as people are not being diagnosed and treated and are also unwilling to challenge the GP's decision. There were also reports of some GP receptionists not being particularly helpful which also creates barriers to access.

4.1.4 Experiences at hospital

It was suggested by a number of participants that hospital staff do not always understand the language and cultural needs of patients which can also create barriers. An example was given from Rochdale where a South Asian woman was distressed and unable to communicate to staff that she wanted to wear her head scarf. Other examples given included

4.1.5 Key issues at a glance

- It is important to acknowledge that many of the barriers affecting BME communities also affect the mainstream population
- Communication is an issue: people do not know who to contact to get help
- There are issues around trust and fear of approaching GPs and other professionals
- It was also suggested that people may feel overwhelmed by the number of agencies that need to be dealt with
- People may not always recognise that they are a carer and many people are not registered as carers by their GP
- Services are Eurocentric and there is often a lack of knowledge of different cultures among professionals
- BME and less heard communities may not recognise the term dementia

- There may be greater reluctance to come forward in some cultures, but we should not make stereotypical assumptions about BME groups always caring for family members
- There is a stigma surrounding diagnosis. Many people worried about getting negative perceptions from professionals.
- People from diverse backgrounds are not represented in local authorities and services
- Limited dialogue between minority communities and service providers exists
- Participants suggested that diverse communities are not hard to reach, instead they are easy to ignore
- It was also widely accepted that cuts to spending on services has made this situation worse

5 Ensuring people from less heard communities access services

A number of suggestions regarding improving access to services by less heard communities were made by participants. These are summarised below:

- Publicise dementia awareness within communities through radio, television and social media
- Use posters and aids with pictures and simple language to publicise services
- Build relationships and trust within communities by holding events/having a dialogue
- Make processes involved in accessing services transparent
- Education in schools – teach children about dementia from a young age
- Identifying key people in less heard communities – make sure we know who to contact to publicise messages
- Education within less heard communities to dispel myths and stigma around dementia
- Make it easier for people to identify themselves as carers
- Describing dementia as a disease of the brain has been helpful within communities where there are high levels of stigma
- Need for flexible support for people with dementia and their carers
- Identify where people in the community are living.

The following good practice example was highlighted by participants:

Good practice example 1

The Alzheimer's Society is developing the Information Programme for South Asian Families (IPSAF) to help carers build their understanding, knowledge and skills. Information will all be verbal and visual rather than in written form. A Bollywood-inspired DVD has been produced in English and Hindi, for example, which people will also be able to take home to share. However, the Hindi version has been identified as inappropriate by many of the communities in Rochdale. People cannot understand the video and the local partner organisations have been told that if they want to change the video they will have to find funding.

6 CONCLUSION

The findings from the Listening Event resonate with the issues highlighted from the literature: there is a need to improve less-heard communities' access to dementia-related services. It seems clear that awareness-raising of dementia is needed among Salford's communities and knowledge of Salford's diverse communities and their needs also should be disseminated among professionals and service-providers. However, currently there are gaps in our knowledge which need to be informed by gathering evidence. There was a strong commitment to improving access to services and increasing awareness of dementia among less heard communities among participants. However, it was acknowledged that more work needs to be done in Salford to identify their needs and to ascertain what is understood by dementia and in order to facilitate this, more joined up working between service providers is necessary.

A recurrent theme raised at the Listening Event was that we cannot make assumptions about groups and communities. It was also recognised that there is a need for the public to be aware of the issues and processes involved in accessing dementia related services. There is also a need for greater awareness of the needs of different communities by professionals and organisations delivering services. It was suggested that enhancing communication and dialogue should be at the heart of any strategy to improve access and service provision.

Participants were asked to identify the next steps and future priorities for action and these are summarised below:

7 NEXT STEPS

- ~ There is a need for awareness raising among diverse communities in Salford regarding dementia and in terms of available services: it was suggested that Dementia Awareness Week would be a useful time to publicise information and that empty shops in Salford precinct could be used to provide a high street presence and base to talk to people in the community
- ~ More knowledge is needed about the needs of Salford's diverse communities in relation to dementia
- ~ There is a need for cultural awareness training for professionals and service providers
- ~ A central 'hub' in Salford would address a number of issues around dealing with multiple agencies and lack of signposting to services
- ~ Need to engage with community organisations
- ~ Include people with dementia as part of the seminars
- ~ Look at what is happening at a local and national level to determine whether there is good practice that we can learn from

8 REFERENCES

All-Party Parliamentary Group on Dementia, (2013) *Dementia does not discriminate: the experiences of black, Asian and minority ethnic communities*, London, APPG

Department of Health (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*, London, Department of Health

Catalyst event report on identifying the gaps in dementia research: Opportunities for novel approaches through collaborations, Wednesday, 22nd January 2014

Lievesley, N. (2010). *Older BME People and Financial Inclusion Report: the future ageing of the ethnic minority population of England and Wales*, London: Runnymede Trust and Centre for Policy on Ageing. Retrieved from <http://www.runnymedetrust.org>

Moriarty, J., Sharif, N. and Robinson, J. (2011) SCIE Research Briefing 35: Black and minority ethnic people with dementia and their access to support and services, London, Social Care Institute for Excellence

Office for National Statistics (2013a). Immigration patterns of non-UK born populations in England and Wales in 2011. London: Home Office (17 December 2013). Retrieved from <http://www.statistics.gov.uk/>

Office for National Statistics (2013b). What does the 2011 census tell us about the “oldest old” living in England and Wales. London: Home Office (6 December 2013). Retrieved from <http://www.statistics.gov.uk/>

Torres, S. (2012). International migration: patterns and implications for exclusion in old age In T. Scharf & N.C. Keating (Eds.) *From Exclusion to Inclusion in Old Age: A Global Challenge*. Bristol: Policy Press.

White, P. (2007). Migrant populations approaching old age: prospects in Europe. *Journal of Ethnic and Migration Studies*. 32, 1283-1300. DOI: 10.1080/13691830600927708.

Williamson, T. (2012) *A Stronger Collective Voice for People with Dementia*, London, JRF

8 APPENDIX 1: The Listening Event



Diversity, inclusivity and dementia event

Monday 10th March, 2014

Venue: The Emmanuel Centre, 174 Langworthy Road, Salford, M6 5PN

Time: 9.30 at venue for 10.00 start

Group discussion 1

What do you understand by 'dementia'?

Group discussion 2

What do people in 'your community' understand by the word dementia?

Feedback to whole group

Activity 2 - Facilitator to read case study to each group

J is 18 years old and attends Sixth Form College and hopes to go away to university next year. J lives with both parents and a younger sister, aged 13. One of J's parents is disabled and J's other parent is the carer. Recently J has noticed that the caring parent has been 'under the weather' and very irritable, often becoming angry at relatively minor issues. At first J put this down to tiredness due to their caring responsibilities, but some troubling instances have occurred, including forgetting to prepare meals and attend hospital appointments. J became extremely concerned on arriving home to find the sister locked out of the house, the disabled parent locked in the house, and was unable to locate the caring parent. The caring parent was later brought home by a neighbour who found them in a confused state walking in the

local park. J doesn't know what to do about the family's problems and it is now taking a toll on J as hopes to go to university and the well-being of the family are in jeopardy.

Discussion points regarding case study-

What are the important issues in this situation?

If someone in your family had these problems what would you do?

What support do the members of this family need?

If someone in your community had these problems what would happen?

What barriers do you think that there are to people from diverse backgrounds accessing services?

How can we make sure people from diverse backgrounds can access services?

Feedback (wider issues and themes)

What Next?

ⁱ Black and Minority Ethnic (BME) or Black, Asian and Minority Ethnic (BAME) are the terms normally used in the UK to describe people of non-white descent. We use BME as an encompassing term.