



University of
Salford
MANCHESTER

1967 • 2017 50 YEARS



Salford CVS

Making a difference in Salford



**Salford Clinical
Commissioning Group**

Salford City Partnership

Promoting diversity and inclusiveness in dementia services in Salford

Anya Ahmed, Mark Wilding, Rita Haworth-Lomax & Su McCaughan
University of Salford

Promoting diversity and inclusiveness in dementia services in Salford

Anya Ahmed, Mark Wilding, Rita Haworth-Lomax & Su McCaughan

Salford Institute for Dementia

January 2017

Contact

Dr Anya Ahmed

Email: a.ahmed@salford.ac.uk

Tel: 0161 295 6632

<http://www.salford.ac.uk/salford-institute-for-dementia>



This project was funded by the Joint Health and Wellbeing Innovation Fund 2015, which was supported by Salford Clinical Commissioning Group and Salford City Partnership, and administered by Salford Community and Voluntary Services.

Executive Summary

Background to the project

Although dementia is now recognised as the most serious health and social care challenge facing UK society, there is little knowledge of the experiences of Black and Minority Ethnic (BME) people with dementia. The National Dementia Strategy states that health and social care services should take account of BME dementia needs; yet, service providers report challenges in including BME people and there is evidence that people from BME backgrounds are currently being 'failed' by the system. Additionally, among the UK's BME population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. Further, people from BME backgrounds are underrepresented in dementia services and present to services late.

This research, funded by the Joint Health and Wellbeing Innovation Fund, has been undertaken by a team at the University of Salford, led by Dr Anya Ahmed. It was timely to conduct this study as Salford's minority ethnic population has increased and diversified over the last decade and these trends are set to continue.

Project aims and objectives

The aims of the study were: to improve access to dementia services for BME communities in Salford; increase carer identification and registration; raise awareness of the needs of Salford's diverse communities; and to increase staff knowledge/develop evidence-based decision-making relating to minority communities who may access dementia services/general health and social care related services in Salford.

The aims were met by addressing the following objectives:

1. Mapping existing service provision in Salford.
2. Gathering the views of service providers and community members.
3. Identifying barriers and facilitators to minority communities accessing existing dementia services/general health and social care related services in Salford.
4. Identifying the aspirations of minority communities for future dementia services/general health and social care related services in Salford.
5. Establishing the levels of staff (service provider) knowledge and understanding of the needs of minority communities who may access dementia services/general health and social care related services in Salford.

Methodology and methods

Primary research was underpinned by a qualitative methodology, which was appropriate to explore the detail of people's lived experiences in relation to dementia, and access to services and support in Salford. The data is analysed through thematic analysis. Some of the data collected through the interviews and focus groups also feeds into a discussion of economic and social value in order to attempt to highlight the potential benefits for the community as well as costs.

The data collection methods were threefold, comprising:

1. Semi-structured interviews with representatives from BME communities in Salford (n=12).
2. Focus groups with representatives from BME communities in Salford (n=6).
3. Semi-structured interviews with key stakeholders (n=30).

Findings from community members

Taking the semi-structured interviews and focus groups together, we engaged with participants from a wide range of visible minority backgrounds, from those born in the UK, to established migrants, and more recent immigrants, including refugees and asylum seekers. For the purpose of our analysis (and to maintain anonymity) we disaggregate community members by gender and into the following broad groups:

- African-Caribbean ancestry
- Chinese
- Central African
- East African
- Jewish
- Middle Eastern
- North African
- South Asian
- Southern African
- West African/West African ancestry

Knowledge and awareness of dementia

- The findings from community members suggest varying levels of knowledge about dementia among Salford's BME communities, with the majority of participants indicating an intermediate level of knowledge.

Community views of dementia

- Participants were less confident about levels of knowledge and understanding of dementia in their communities. On the one hand, some participants suggested that *dementia is viewed negatively* and even seen as 'madness', while on the other it may be *simply regarded as part of the ageing process*.

BME communities and access to services in Salford

- Participants were aware of some members of their communities accessing dementia services in Salford, yet, the majority of participants indicated that there is a *reliance on family care*. Significantly, however, this was seen as arising, at least in part, due to *a lack of suitable/affordable care, or community members not being aware of services that are available*.
- While participants were all active members of their communities, and therefore had some awareness of services, it was felt that other *community members had much less knowledge of available services*.

Barriers to accessing services

- The main barrier to promoting inclusion and diversity in dementia services in Salford appears to be at the start of the Dementia Care Pathway. This is the *information gap*, which is connected to *language, culture and participation in social networks* which extend outside of their own community, but also the ways in which services attempt to disseminate information and engage with BME communities.
- Other barriers, which appear further down the dementia care pathway, include *financial costs, NHS waiting times, and culturally appropriate diagnostic tools and care*.

Policies and initiatives to promote inclusiveness

Community member suggestions for making dementia services more diverse and inclusive included:

- Improving the availability of interpretation services,
- Furthering efforts to disseminate information and engage with communities,
- Improving the visibility of dementia centres,
- Creating more training and volunteering opportunities for Salford's diverse communities.

Challenges to services being inclusive

- Participants saw the main challenges to promoting diversity and inclusiveness in dementia services in Salford as coming not from the communities themselves or local services, but rather the national policy context, including *austerity* and the associated impact on local services and the *availability of English language classes*, along with *welfare conditionality* and *immigration law*.

Findings from stakeholders

Participants in this part of the research were sampled purposively regarding their organisation and role, and there was also representation across a range of organisational levels, from strategic to operational. Included in this sample, were 30 participants from 26 organisations. For the purpose of our analysis (and to maintain anonymity) we disaggregate stakeholders into four broad groups:

- Older Peoples' Services
- Dementia Specific services
- Community / General Organisations
- Health and Social Care Providers

Awareness of the needs of BME communities in Salford

- There was variability regarding the levels of knowledge and awareness of the needs of BME communities among stakeholders, with Dementia Services Providers in particular not having any experience of working with BME communities in Salford.

BME communities accessing and using services in Salford

Stakeholders reported low take-up of services and explained this in terms of:

- *Salford's population being predominantly White British*. Several stakeholders noted that Salford's population was comprised of mainly White British people, and that people from BME communities

were in a minority. Because of this some felt that the low numbers of BME communities accessing their services was proportionate to the wider population's ethnic constitution.

- *Reluctance of BME communities to access health and dementia care and support.* Health and Social Care Providers tended to report that Salford's BME communities did come forward to use their services, but that in the main people presented much later with health problems than the white population. Given the reluctance of people from BME communities to access health care and support services for more general health matters, it was not surprising to find that there was a greater reluctance to come forward for dementia treatment, care and support.

Barriers to BME communities accessing services

A number of barriers to BME communities accessing services were identified by stakeholders, which can be summarised as follows:

- *Stigma, language and culture.* Several stakeholders suggested that language barriers, cultural factors and stigma surrounding dementia could prevent people from BME communities coming forward and accessing services. However, many also acknowledged that they did not know for certain how such barriers operated. Stakeholders also indicated that the barriers to BME communities accessing general health services were even more apparent in mental health and dementia services.
- *Lack of knowledge of services and challenges in navigating systems.* Almost all of the stakeholders who participated in the research felt that there was a lack of knowledge among Salford's BME population about the services they provided, and that this operated as a significant barrier to accessing these. Additionally, some stakeholders suggested that people from BME communities may not be familiar with navigating (often complicated) systems and that this would act as a further barrier.
- *Historical lack of engagement and representation of BME communities in Salford.* Several stakeholders felt that a legacy of lack of engagement with and representation of BME communities in health and social care services has contributed to the current situation where people from these communities do not access services in a proportionate number.
- *Assumptions that care is provided by the family.* A number of stakeholders suggested that people from BME communities did not come forward to use services as care was provided by the family.
- *Lack of confidence in services.* A number of stakeholders suggested that people from BME communities in Salford may not come forward to use services due to not believing that such services were able to meet their needs, or due to a lack of trust.
- *Due to dementia itself (the condition).* Some stakeholders indicated that living with dementia could potentially act as a barrier to people using services since there could be a denial of the symptoms, or the condition could impact on people's ability to engage.
- *A small number of stakeholders suggested that no barriers existed to accessing their services.* Some providers commented that although take up by of their services by BME communities was very low, that there were no significant barriers preventing access.

Policies and initiatives in place to address the needs of BME communities

Stakeholders were asked about whether their organisations had policies in place to specifically meet the needs of BME communities, and whether they had these in place in relation to dementia. All reported that they had general equality and diversity policies in place.

Good practice identified

Stakeholders were asked to identify any areas of good practice or initiatives that had been developed to promote inclusion of BME communities in dementia services. These included:

- Good practice example 1: Together Dementia Support.
- Good practice example 2: Heathlands Village.
- Good practice example 3: Side by Side.

Challenges to providing inclusive services

Stakeholders were asked to identify any challenges for their organisations providing inclusive services and these can be broadly described as 'structural': in terms of wider contextual issues, including funding and resource constraints and a historical lack of evidence and information sharing; and a lack of organisational and individual knowledge of how best to meet the needs of Salford's BME communities.

- *Funding/resource constraints.* Stakeholders indicated that limited funding - particularly in the current climate where third sector organisations have to bid for funds – is a significant barrier to providing inclusive services. There appeared to be a recognition of what needed to be done to achieve this, but funding and resource constraints prevented it.
- *Evidence and lack of Information sharing.* Some stakeholders felt that the way people's ethnicity was recorded, a lack of evidence of demand for services from BME communities, compounded by a lack of information sharing among health and social care and dementia services, also presented challenges to inclusiveness.
- *Lack of knowledge of how to meet BME communities' needs.* Several stakeholders stated that they had very little experience of working with BME communities, and did not feel confident or knowledgeable about the needs of diverse populations. A lack of representation of people from Salford's BME communities was also considered to be problematic.

Overcoming barriers and making services more accessible

Stakeholders were asked to identify ways to overcome the barriers to service provision and increase accessibility and inclusiveness. A number of suggestions were put forward: the need to increase knowledge of other cultures; increasing outreach and engagement activities; evidencing need; raising awareness of dementia among BME communities; and increasing BME representation.

- *Increasing knowledge of other cultures.* Increasing knowledge of other cultures was felt to be necessary by almost all participating stakeholders. This included: understanding how BME communities understood and experienced dementia which would involve training for GPs and health and social care staff; greater representation of BME staff; and investing time into developing appropriate services.
- *Increasing outreach and engagement activities.* Stakeholders suggested that increasing outreach and engagement activities was necessary if services were to be more inclusive. This was thought to involve developing better links with different communities, having a strategic and flexible approach to engagement, targeting services to the areas where BME communities are located and 'reaching out' to

Promoting diversity and inclusiveness in dementia services in Salford

communities rather than expecting them to come forward to access services. It was also felt that much more needed to be done to publicise services and there was a need for BME representation.

- *Evidencing need.* Some stakeholders suggested that it was necessary to identify levels of need in order to effect appropriate levels of provision for Salford's BME communities experiencing dementia.
- *Raising awareness of dementia among BME communities.* Several stakeholders suggested that it was important to raise awareness of dementia among Salford's BME communities, as many people were not 'in the system' which meant that they would not receive care or support

Recommendations

- There is a need provide education about dementia to Salford's BME communities as there is often a lack of insight from people living with dementia and their family members. The way this is delivered needs to be culturally appropriate both in terms of content and the way it is disseminated.
- There is an additional and related need to provide information and publicity about the availability of dementia services through a range of culturally appropriate media (for example, community radio stations and posters), to dispel myths and remove the stigma surrounding dementia.
- There is a need for increased awareness of the needs of BME communities for service providers, including gatekeepers (GPs) and other organisations.
- There is a need for staff training regarding how best to approach patients within Salford's diverse communities.
- Employing health and social care workers from BME backgrounds would also promote approachability of services.
- Health and social care organisations need to be present in community spaces to successfully engage with Salford's BME communities.
- Dementia Friends needs to extend to Salford's BME communities.
- There needs to be representation of BME community members on boards and committees relating to dementia.

Anya Ahmed, Mark Wilding, Rita Haworth-Lomax & Su McCaughan
January 2017

Acknowledgements

Many people and organisations have been involved in this project and we would like to thank everyone who contributed, particularly members of Salford's BME population. We would also like to thank those people who participated in the research from organisations working in the fields of health and social care, older people's services, dementia specific services, and community organisations.

Special thanks go to Caroline Allport, Irfan Syed and Andy Walker for their help in making contact with Salford's BME communities and stakeholders, and for their support throughout the project. Finally, thanks to Salford Clinical Commissioning Group, Salford City Partnership and Salford CVS for supporting this project through the Joint Health and Wellbeing Innovation Fund 2015.

Project Team

Dr Anya Ahmed Senior Lecturer, Social Policy, University of Salford. Anya has a background in social policy and sociology. Prior to becoming an academic she was previously employed by a local authority and housing association in policy and housing management roles. She has also worked as a freelance trainer and consultant. In an academic context, Anya has led a range of externally funded research projects on the experiences of less heard communities, for example *Somalis in London/Somalis in Europe* and the Somali Dementia Aware Project (Camden). She writes about different forms of migration (forced, economic, lifestyle). She is principal investigator on the Somali Dementia Aware Project in Camden and the Salford BME and Dementia study. She has expertise in qualitative research methodologies, in particular biographical approaches and structural narrative analysis. She is a member of the ESRC Peer Review College, a member of the Social Policy Association Executive, an Editorial Board member for the Journal *Social Policy and Society* and a Board Member at St. Vincent's Housing Association.

Dr Mark Wilding Lecturer, Social Policy, University of Salford. Mark has eight years of postdoctoral university teaching experience in the UK and South Korea. During this time, he has researched a wide range of policy areas including employment, housing, social care, and social enterprise, among others. His work has drawn on research methods including focus groups and semi-structured interviews, along with quantitative analysis of both primary and secondary datasets. This work has been published in high level journals including *Administration & Society*; *Policy Studies*; and *Policy Sciences*; and he has also presented at numerous international conferences. Mark has produced policy evaluations and reports for local and central government and non-profit organisations in the UK and South Korea. He was on the editorial team of *Korean Society and Public Administration* for five years until 2016 and has acted as a peer reviewer for a range of journals including *Journal of Public Policy*; *Asia Pacific Law Review*; and *International Review of Public Administration*.

Ms Rita Haworth Senior Lecturer in Social Policy at the University of Salford. Previously Rita has worked for the probation service, been an Executive member of The Social Policy Association and most recently A Director/Trustee of Healthwatch. Rita leads a number of modules including Introduction to Social Policy, Health, Wellbeing and Social Policy and Health and Social Care Policy. She is also the module lead and co-ordinator for the Community Placement and Social policy dissertation. Rita's main academic interests are the history of social policy, health policy, older people and gender issues. She has undertaken research in the areas of widening participation, personal development planning and public and patient participation in decision making in local health care planning. Her recent research activities have concluded with the delivery of a number of national and international conference papers and publications in journals such as the *British Medical Journal* and the journal of *Dementia Care*.

Ms Su McCaughan Lecturer in Social Work (Practice Learning) at the University of Salford. Su is a registered social worker with the Health Care Professions Council (HCPC) and an HCPC CPD assessor. Her practice career was as a probation officer with over 20 years' experience and she made the transition to Higher Education in 2006. Su is an off-site practice educator and a Fellow of the Higher Education Academy. Su's teaching and research reflects her social work practice experience, on practice education and particularly how student social workers learn in non-traditional settings. Su has a strong interest in collaboration with students including a recent presentation at the National Organisation of Practice Teachers (NOPT) conference on 'Experiences of black students in practice placements'; and a current project on developing skills for case recording in the digital age. Promoting diversity and inclusiveness in dementia services in Salford aligns with the impact of Su's personal experience of dementia combined with supporting placements in dementia services in Salford and Greater Manchester.

Contents

1. Introduction to the study	12
2. Rationale for the study	12
3. Aim and objectives of the study	13
4. Report structure	13
5. Methodology and methods	13
6. Understanding dementia	16
7. The policy context	17
8. Dementia services in Salford	20
9. Health outcomes of BME communities in Salford	22
10. Dementia and BME Communities	23
11. Findings and analysis: community members	26
12. Findings and analysis: service providers/stakeholders	41
13. Conclusion	55
14. Recommendations	57
15. Appendices	58

1. Introduction to the study

Dementia is now recognised as the most serious health and social care challenge facing UK society, due to an ageing population¹. At the 2011 Census, 16% of the UK population were aged 65 and over, 14% of which were aged 85 and over - the population group that is growing fastest². Migration patterns from the 1950s and 1960s mean that the UK is now home to an ageing Black and Minority Ethnic (BME) population³. Significantly, it has been estimated that there are 25,000 people with dementia from BME communities in England and Wales, and this figure is predicted to rise to 50,000 by 2026 and 172,000 by 2051⁴. However, there is little knowledge of the experiences of BME people with dementia, which in the UK includes people from a range of ethnic backgrounds. The National Dementia Strategy sets out expectations for health and social care services to take BME dementia needs into account; yet, service providers have commented on the difficulties of including people from BME communities⁵, and there is evidence that people from BME backgrounds are currently being ‘failed’ by the system⁶. Additionally, among the UK’s BME population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. Further, people from BME backgrounds are underrepresented in dementia services and present to services later⁷.

There remains very little knowledge and research on BME communities and dementia, and it has been suggested that there is a need to gather more information and engage further with BME communities in order to fill gaps in knowledge about their service needs⁸ to successfully implement the National Dementia Strategy⁹. This research, commissioned and funded by Salford CVS has been undertaken by a team at the University of Salford, led by Dr Anya Ahmed.

2. Rationale for the study

It was timely to conduct this study as Salford’s minority ethnic population has increased and diversified over the

¹ All-Party Parliamentary Group on Dementia (2013) *Dementia Does Not Discriminate: The Experiences of Black, Asian and Minority Ethnic Communities*. London: APPG.

² Office for National Statistics (2013) *What Does the 2011 Census Tell Us About Older People?* <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/what-does-the-2011-census-tell-us-about-older-people-/index.html>

³ Ahmed, A. (2015) UK Migration and Welfare Regimes. In U. Karl and S. Torres *Ageing in the Context of Migration*. London: Sage.

⁴ 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.

⁵ Williamson, T. (2012) *A Stronger Collective Voice for People with Dementia*. London: JRF.

⁶ 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.

⁷ 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.

⁸ Botsford and Harrison Denning (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

⁹ Introduced in 2009 by the Department of Health, this strategy provides a framework within which local services can deliver quality improvements to dementia services and address health inequalities relating to dementia; provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services; and provides a guide to the content of services for dementia.

last decade. It is estimated that there are currently 25,000 people with dementia (PWD) from BME communities in England and Wales and this figure is projected to increase to 50,000 by 2026, and 172,000 by 2051¹⁰. The National Dementia Strategy emphasised that health and social care staff should take account of BME dementia needs, yet service providers report challenges in including BME people¹¹. Additionally, among the UK's BME population there are lower levels of awareness of dementia and higher levels of stigma associated with the condition¹². However, the research and evidence base is limited.

3. Aims and objectives of the study

The aims of the study were: to improve access to dementia services for BME communities in Salford, increase carer identification and registration, and raise awareness of the needs of Salford's diverse communities; to increase staff knowledge/develop evidence-based decision-making relating to minority communities who may access dementia services/general health and social care related services in Salford.

The aims were met by addressing the following objectives:

1. Mapping existing service provision in Salford.
2. Gathering the views of service providers and community members.
3. Identifying barriers and facilitators to minority communities accessing existing dementia services/general health and social care related services in Salford.
4. Identifying the aspirations of minority communities for future dementia services/general health and social care related services in Salford.
5. Establishing the levels of staff (service provider) knowledge and understanding of the needs of minority communities who may access dementia services/general health and social care related services in Salford.

4. Report structure

The report is structured in the following way: first we present the methodological approach and methods used in the study. We then discuss dementia and review the relevant policy context, placing dementia services provision in Salford within this context before reviewing the health outcomes of BME communities in Salford. An overview of dementia and BME communities is then presented to contextualise the data findings and analysis from service users and service providers. We then present a final discussion and conclusion and make recommendations for further action.

5. Methodology and methods

The project involved a review of existing data and begin with a detailed review of the composition, demography,

¹⁰ 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.

¹¹ Williamson, T. (2012) *A Stronger Collective Voice for People with Dementia*, York: Joseph Rowntree Foundation.

¹² Moriarty, J., Sharif, N. and Robinson, J. (2011) *Black and Minority Ethnic People with Dementia and Their Access to Support and Services* (SCIE Research Briefing 35). London: Social Care Institute for Excellence.

projections and location of BME communities in Salford¹³. The report includes a review of the literature and policy on minority communities and dementia and access to dementia related services. We reviewed and identified best practice and highlight key learning points which can be applied to the context of Salford.

Primary research was underpinned by a qualitative methodology, which was appropriate to explore the detail of people's lived experiences in relation to dementia, access to services and support in Salford. The data collected presented is analysed through thematic analysis. Some of the data collected through the interviews and focus groups also feeds into a discussion of social and economic value, in order to attempt to highlight potential costs and benefits for the community. In recruiting participants, we drew on contacts made with organisations working with Salford residents with dementia, through the Listening Event and seminars carried out in 2014. Dr Anya Ahmed, Dr Mark Wilding, Ms Rita Haworth-Lomas and Ms Su McCaughan conducted the fieldwork with service providers/stakeholder and members of Salford's BME community.

The primary qualitative research was complemented with secondary analysis of quantitative data. This took two strands: (1) An examination of the number of Memory Assessment and Treatment Service (MATS) open cases of people from BME backgrounds with dementia in Salford, and comparing these with estimated figures based upon the size of Salford's BME population; (2) A discussion of economic and social value in order to understand the health, social care, and wellbeing costs and benefits of initiatives to promote diversity and inclusiveness in dementia services in Salford.

The grant was awarded in January 2016. The gathering of baseline data of population demographics and projections began in February and ethical approval was applied for. Research instruments were designed and piloted (internally) in March. The literature review was conducted from March to June 2016. Data collection was undertaken from April to October. Data analysis and report writing took place in November and December. The research was granted ethical approval by the School of Nursing, Midwifery, Social Work and Social Science at the University of Salford, and was conducted in accordance to ethical principles in social research.

The data collection methods were threefold, comprising:

1. *Semi-structured interviews with representatives from BME communities in Salford (n=12)*

Participants were sampled purposively according to community to attempt to reflect the range of visible BME communities in Salford. Included in this sample, were 12 participants from five organisations as follows:

- Salford Forum for Refugees and People Seeking Asylum
- University of Salford students
- Visible Outcomes
- Wai Yin Society
- Yemeni Community Association in Greater Manchester

¹³ This was also facilitated by the Salford BME Health Needs Assessment compiled by Dr Nick Riches.

2. *Focus groups with representatives from BME communities in Salford (n=6)*

This part of the study included six focus groups from three separate organisations, making a total of 36 participants:

- Salford Forum for Refugees and People Seeking Asylum
- Salford Healthy Communities
- University of Salford students

Taking the semi-structured interviews and focus groups together, we engaged with participants from a wide range of visible minority backgrounds, from those born in the UK, to established migrants, and more recent immigrants, including refugees and asylum seekers. For the purpose of our analysis (and to maintain anonymity) we disaggregate community members by gender and into the following broad groups:

- African-Caribbean ancestry
- Chinese
- Central African
- East African
- Jewish
- Middle Eastern
- North African
- South Asian
- Southern African
- West African/West African ancestry

3. *Semi-structured interviews with key stakeholders (n=30)*

Participants in this part of the research were sampled purposively regarding their organisation and role, and there was also representation across a range of organisational levels, from strategic to operational. Included in this sample, were 30 participants from 25 organisations as follows:

- Age UK Salford
- Alzheimer's Society (Greater Manchester & Wirral)
- BME Health and Wellbeing (Rochdale)
- City of Trees
- General Practitioner Practice
- Greater Manchester West Mental Health NHS Trust
- Healthwatch
- Humphrey Booth Resource Centre

Promoting diversity and inclusiveness in dementia services in Salford

- Inspiring Communities Together
- Pennine Acute Hospitals NHS Trust
- Public Health Specialist Registrar
- Retired GP
- Salford Carers Centre
- Salford City Council
- Salford Community and Voluntary Services (CVS)
- Salford Dementia Champions
- Salford Health Matters
- Salford Integrated Care Organisation (Salford Together)
- Salford Involve
- Salford NHS Clinical Commissioning Group
- Salford Royal NHS Foundation Trust
- Six Degrees
- The Fed
- University of Salford Institute for Dementia

For the purpose of our analysis (and to maintain anonymity) we disaggregate stakeholders into four broad groups:

- Older Peoples' Services
- Dementia Specific services
- Community / General Organisations
- Health and Social Care Providers

We present the findings and thematic analysis from community members and stakeholders separately below, but draw these together in our conclusion and recommendations.

6. Understanding dementia

Dementia is now recognised as a growing national and global challenge, and has become one of the most significant health and care issues worldwide. The number of people living with dementia (globally) is estimated at 44 million, predicted to almost double by 2030¹⁴. In England, it is estimated that 676,000 people have

¹⁴ Alzheimer's Disease International (2015) *World Alzheimer's Report 2015: The Global Impact of Dementia* <https://www.alz.co.uk/research/world-report-2015>

dementia¹⁵. Consequently, as the population ages, the economic burden of dementia is expected to rise exponentially¹⁶. The term 'dementia' is used to describe a set of neurological conditions which cause gradual and long-term impairment to cognitive and physical functioning. The World Health Organisation defines dementia as follows:

Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

(WHO, 2016)¹⁷

7. The Policy Context

Since the NHS reforms in 2013, resources are distributed at regional level through Clinical Commissioning Groups (CCGs), which are responsible for commissioning health services, including dementia related healthcare services as identified by Joint Strategic Needs Assessments (JSNA) of people with dementia. In every CCG, there is a head of engagement responsible for:

- The workforce
- Local practices (GPs)
- Local communities

Dementia services – from pre-diagnosis to end of life care - are provided by a range of public sector (NHS, social care services), private sector, voluntary sector and voluntary sector (charitable and BME specific) organisations. The National Institute for Health and Care Excellence¹⁸ (NICE) has established a 'Dementia Care Pathway', which outlines how a person with dementia should experience services and how different services should connect.

¹⁵ Alzheimer's Disease International (2015) *World Alzheimer's Report 2015: The Global Impact of Dementia* <https://www.alz.co.uk/research/world-report-2015>

¹⁶ Department of Health (2013) *Dementia: State of the Nation*. London: Department of Health.

¹⁷ World Health Organisation (2016) *Dementia Fact sheet No 362* <http://www.who.int/mediacentre/factsheets/fs362/en/>

¹⁸ An executive non-departmental public body of the Department of Health in the United Kingdom.

The Dementia Care Pathway can be summarised as having broadly six stages:

Figure 1. The Dementia Care Pathway

Prevention (Awareness and risk reduction)	Identification	Assessment and Diagnosis	Early Intervention and Treatment	Living well with dementia	End of life care (last years of life care)
--	----------------	-----------------------------	--	------------------------------	---

1. **Prevention (or awareness and risk reduction)**, where awareness raising, risk reduction and the promotion of healthy living feature;
2. **Identification**, where people would be referred to the Memory Service, usually following a GP appointment;
3. **Assessment and Diagnosis**, when the Memory Service (or other specialist agency) carries out a full assessment. At this stage, if someone is given a diagnosis of dementia this would be explained;
4. **Early Intervention and Treatment**, from this stage, people with dementia are given an annual review and offered support and medication where appropriate. At this stage care-givers should also have their needs assessed and access to services should be explained;
5. **Living well with dementia**, people with dementia should have their needs regularly reviewed and appropriate interventions should be in place. Opportunities to plan for future care (and long term care) should be provided alongside support and coping strategies for care-givers;
6. **End of life care (last years of life care)**; people with dementia should be added to the Palliative Care Register when they approach the end of their life and appropriate support should also be in place.

People with dementia from BME communities and their carers face barriers in accessing services and often present to services at a later stage and when their dementia is more advanced. In many BME communities there is no word for ‘dementia’ which makes framing, describing and understanding the disease more of a challenge. There are also lower levels of awareness of dementia and often higher levels of stigma in some communities, which again can make identifying the disease accessing services problematic. Lower levels of knowledge of dementia is also believed to contribute to higher levels of stigma: in some communities, dementia is associated with mental illness¹⁹. Additionally, religion can influence people’s perceptions of dementia and how they engage (or not) with support services²⁰. Religious beliefs can frame dementia as a punishment for behaviour in a past life²¹; a punishment from God²²; as possession or witchcraft²³. Services are often not culturally sensitive or appropriate, which can also create obstacles to access. Additionally, BME communities are stereotyped as ‘looking after their own’, which can mean that providers are reluctant to

¹⁹ Moriarty, J. (2015) Accessing Support and Services. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

²⁰ Moriarty, J. (2015) Accessing Support and Services. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing

²¹ Hinton, L., Nhauyen Tran, J., Tran, C. and Hinton, D. (2008) Religious and Spiritual Dimensions of the Vietnamese Dementia Caregiving Experience. *Hallym International Journal of Ageing*, 10: 139-160.

²² Adamson, J. (2001) Awareness and Understanding of Dementia in African/Caribbean and South Asian Families. *Health and Social Care in the Community*, 9: 391-396.

²³ Jett, K.F. (2006) Mind-Loss in the African American Community: Dementia as a Normal Part of ageing. *Journal of Aging Studies*, 20: 1-10.

intervene²⁴. It is also important not to underplay the role of language: almost all minority ethnic people living in the UK aged 65 and over were born outside the UK, and even those who speak fluent English can gradually lose this ability as dementia progresses²⁵. Further, those people are not fluent in speaking English, are at a disadvantage when using health services²⁶. For example, people may not be aware of available resources, or even if they access resources they may find it difficult to communicate with staff or to comprehend treatment options²⁷.

Therefore, low levels of awareness of dementia (and lack of knowledge of preventative measures), compounded by stigma surrounding the disease pose challenges to people with dementia from BME communities in approaching health care services. General Practitioners essentially act as gatekeepers to accessing other primary care services and secondary care services and would be the first point of contact in the Dementia Care Pathway for someone who thought that they or a family member was showing symptoms of dementia. However, evidence suggests that GPs' awareness and understanding of dementia is not always robust, and this can result in a failure to diagnose and refer to other services.

If a person with suspected dementia is referred to the Memory Clinic for diagnosis, there are further challenges facing people from BME communities. Dementia is usually diagnosed by determining cognitive impairment and decline over time and by using screening instruments to measure the type and extent of cognitive impairment²⁸. Originally, diagnostic screening tools were devised to test the majority ethnic group in the UK, and such tools are not appropriate for testing the cognitive function of people with dementia from BME backgrounds. There have been some developments in screening instruments for some BME groups²⁹; however, these diagnostic tools can only be used by bilingual clinicians as the questions are in the original language of older BME community members. Further, there are no instruments which can be used by English only speaking clinicians with an interpreter translating³⁰. Clearly then, there are challenges at the assessment and diagnostic stages of the Dementia Care Pathway for people with dementia from BME communities. This in turn has implications for early intervention, and delays in treatment, and can compromise a person with dementia's ability to live as well as is possible with the condition. Reminiscence work is considered helpful for someone to live well with dementia; however, often, reminiscence therapies are not appropriate for people from a BME background, as British historical and cultural reference points are used³¹.

²⁴ 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.

²⁵ Khan, O. (2015) Dementia and Ethnic Diversity. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

²⁶ Botsford, J., Clarke, C.L. and Gibb, C.E. (2012) Dementia and Relationships: Experiences of Partners in Minority Ethnic Communities, *Journal of Advanced Nursing*, 68: 2207-2217.

²⁷ Moriarty, J. (2015) Accessing Support and Services. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

²⁸ Shah, A. and Zarate Escudero, S. (2015) Dementia and Ethnicity. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

²⁹ For example, the abbreviated Mental Test Score and the Mini Mental State Examination (MMSE)

³⁰ Shah, A. and Zarate Escudero, S. (2015) Dementia and Ethnicity. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

³¹ Ahmed, A., with Yates-Bolton, N. and Collier, E. (2014) *Diversity and Inclusiveness in Dementia: Listening Event Report*. Salford: University of Salford.

Good practice example

BME Health and Wellbeing, a community organisation founded by Shahid Mohammed in Rochdale, produced a DVD on 'Purani Yaadein' (old memories) to raise awareness of Dementia amongst the south Asian community in Rochdale and to capture the 'Purani Yaadein' of the first generation of south Asians who settled in the town.

The making of the film was inspired by the team's personal experiences whose parents arrived in the UK in 1960s to fill the labour shortage in the textile industry. The film captured a number of old memories of people from this early generation as part of the project, which also included community based reminiscing workshops.

The film features interviews from health care professional including Dr Shanu Datta, Consultant Psychiatrist for Older People at Rochdale's Birch Hill Hospital and Julie Mann, Dementia Adviser from the Alzheimer's Society.

It is only very recently³², that attention has been paid to the experiences and needs of people with dementia from BME backgrounds living in residential and nursing care homes. Take-up of care home services is low³³, possibly because of lack of knowledge of such services, issues with referrals and conflicts with religious and traditional patterns of care. Often, family members who are providing support do not identify as 'care-givers', so do not receive support themselves³⁴. Further, Western conventions and values shape decision making processes in end of life care. Additionally, social inequalities among older people can impact on end of life experiences since people's social and economic status during the course of their life is mirrored in the way that their death is perceived³⁵. It is easier to exercise choices and control over end of life if a person is wealthy³⁶ and again this could be an issue facing older BME communities in the UK³⁷, particularly for people with dementia.

8. Dementia Services in Salford

There are a number of organisations in Salford which offer dementia support services. The table below, offers some indication of the breadth and nature of services available locally.

³² Milne, A. and Smith, J. (2015) Dementia, Ethnicity and Care Homes. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

³³ Harrison Dening, K. (2015) End of Life, Dementia and Black and Minority Ethnic Groups. In J. Botsford and K. Harrison Dening (eds) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

³⁴ Ahmed, A., with Yates-Bolton, N. and Collier, E. (2014) *Diversity and Inclusiveness in Dementia: Listening Event Report*. Salford: University of Salford.

³⁵ Kinghorn, K. (2013) Death and the End of Life. In P. Dwyer and S. Shaw (eds) *An Introduction to Social Policy*. London: Sage.

³⁶ Twomey, F., McDowell, D., and Corcoran, G. D. (2007) End-of-Life Care for Older Patients Dying in an Acute General Hospital: Can We Do Better? *Age and Ageing*, 36: 462–464.

³⁷ Ahmed, A. (2015) UK Migration and Welfare Regimes. In U. Karl and S. Torres (eds) *Ageing in the Context of Migration*. London: Sage.

Table 1. Dementia Services in Salford

	<i>Organisation</i>	<i>Description</i>	<i>Website</i>
<i>Statutory</i>	Salford City Council	Provides advice about dementia services in Salford. Works in partnership with NHS Trust's, local groups and Age UK Salford's dementia support service. The Dementia Champions Group has also produced a guide to dementia - what happens at each step.	https://www.salford.gov.uk/health-and-social-care/dementia-support/
	Salford City Council, Salford CCG	Joint Commissioning for older people with dementia in Salford Strategy provides joint commissioning strategy in achieving the vision and supporting older people with dementia.	http://www.salfordccg.nhs.uk/download.cfm?doc=docm93jjjm4n1956.pdf&ver=213
	Salford Memory Assessment Centre.	Working to promote the early identification of dementia	https://www.gmw.nhs.uk/salfordmats
<i>Charities</i>	Salford Age UK	Provides community-based advice, guidance and support to individuals with a diagnosis of dementia.	www.ageuk.org.uk/salford/our-services1/dementia-support-service1/
	Salford Dementia Road Map	Provides high quality information about the dementia journey alongside local information about service	http://dementiaroadmap.info/Salford
	Mind Dementia Services Salford	Is an independent, user focused charity providing quality services to make a positive difference to the wellbeing and mental health of the people of Salford.	http://www.mindsalford.org.uk/
	Alzheimer's society Salford branch	Offer services for those with dementia and their carers.	https://www.alzheimers.org.uk/site/custom_scripts/branch.php?branch=true&bran
<i>Research</i>	Salford Institute for Dementia, University of Salford	Conducts vital research into living well with dementia. The Institute also designs dementia-friendly buildings, gardens, urban spaces ...	http://www.salford.ac.uk/salford-institute-for-dementia/home/our-people
<i>Other third sector</i>	Salford CVS	Challenges partners to effectively engage with and invest in the sector so that local people and communities can help to Improve services for those living with dementia and their carers.	https://www.salfordcvs.co.uk/
	Dementia Care/ Nursing homes	A number of homes provide residential care and nursing support across Salford.	http://www.carehome.co.uk/care-search-results.cfm/searchunitary/Salford/sear

9. Health outcomes of BME communities in Salford

Current BME demographics in Salford

There were 36,488 people in Salford from a BME background (15.6% of the total population) in 2011. This includes members of all groups except White British. The commonest ethnic groups are Other White (which includes European migrants), Black African and White Irish. The wards with the highest proportion of BME communities are Broughton (33%), Ordsall (32%) and Irwell Riverside (29%). The Jewish community is centred in Kersal and Broughton. BME groups in Salford (apart from White Irish) tend to have a younger age structure than the White British population³⁸. There are now 16,085 people in Salford who do not speak English as their main language, with over 70 languages being spoken in total³⁹.

Between 2001 and 2011 Salford's BME population grew by 20,728 (132%) between 2001 and 2011 (compared to a 68% increase seen nationally). The largest increases were seen in the Other White community increased by 7,002 (198%) and the Black African community which increased by 4,645 (655%). There was a 48% increase in the Jewish population to 3.3% of the total Salford population, more than six times the national average⁴⁰.

The proportion of the Salford population born outside the UK is increasing faster than the Greater Manchester average. Based on projected population trends, by 2051 in Salford it is estimated that the BME population will have increased to approximately 90,000 people (31.7% of the total population). Therefore, there will be a particularly noticeable increase in the elderly BME population.

Although there are no official statistics, we estimate that there are at least 100 BME people with dementia in Salford, and this figure is increasing⁴¹. People with dementia, their carer givers and families will benefit through increased awareness and better quality services. Service providers will benefit from being better equipped to meet future needs⁴².

The National Census gives the most accurate account of the size and distribution of different ethnic groups in the UK. The most recent data comes from the 2011 Census, since the ONS mid-year population projections do not include ethnicity data. According to the 2011 Census the population of Salford is 233,933, with a total BME population of 36,488. Table 3 shows the population of each major and minor ethnic group in Salford. The commonest major ethnic group is White, accounting for 90.1% of Salford residents. This is followed by Asian (4.0%), Black (2.8%) and Mixed (2.0%)⁴³.

The most common White group is White British (84.4% of Salford total). There are 2,882 White Irish residents (1.2%) and 193 from a Gypsy / traveller background. Compared with the average North West population the relative size of the White British population is slightly smaller, while the White Irish and Other White groups are

³⁸ Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

³⁹ Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

⁴⁰ Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*, Salford: Salford City Council.

⁴¹ Based on estimates of dementia within the BME population of England and Wales, along Census information on the size of the BME community in Salford.

⁴² Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

⁴³ Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

larger⁴⁴.

The most common Asian ethnic groups in Salford are Indian (1.1%) and Chinese (1.1%), followed by Pakistani (0.8%), Other Asian (0.8%) and Bangladeshi (0.3). Overall the Asian ethnic group is smaller than national and North West populations, with the relative size of the Pakistani community being noticeably smaller. The Black major ethnic group is more than twice the size of the North-West average. This is primarily due to the size of the Black African population (2.3%) which is also bigger than the average for England (1.8%). The Black Caribbean community in Salford (0.3%) is of a similar size to the North-West average. The relative size of the Mixed major ethnic group is similar to the North West and English populations, besides a noticeably larger White/Black African group.

The Arab ethnic group was added for the 2011 Census which showed that it is the 10th largest ethnic group in Salford. In 2011 there were 1,425 people in the Arab ethnic group accounting for 0.5% of the Salford population which is higher than the North-West average⁴⁵.

10. Dementia and BME communities

As already indicated, the numbers of people with dementia from BME communities is expected to increase. The National Dementia Strategy⁴⁶ states that health and social care services should address the needs of people from BME communities, but there is evidence that their needs are not properly met and BME communities are not well-represented in dementia services⁴⁷. Lower levels of awareness about dementia exist among BME populations, and there is also a higher level of stigma surrounding the disease⁴⁸. Additionally, people from BME communities present later to services⁴⁹. Although there is a limited evidence base⁵⁰, it is likely that certain types of dementia, for example, vascular dementia, is more common among BME populations since some risk factors, for example hypertension, diabetes and high cholesterol are more prevalent within such communities. Based on the evidence presented above, it is likely that people from BME communities in the UK experience difficulties at each stage of the Dementia Pathway⁵¹.

Dementia and BME communities in Salford

According to the Black and Minority Ethnic Groups Health Needs Assessment⁵², early-onset dementia is more common in BME groups and BME populations are also less likely to access palliative care. The BME needs

⁴⁴ Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

⁴⁵ Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

⁴⁶ Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. London: Department of Health.

⁴⁷ All-Party Parliamentary Group on Dementia (2013) *Dementia Does Not Discriminate: The Experiences of Black, Asian and Minority Ethnic Communities*. London: APPG.

⁴⁸ 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.

⁴⁹ All-Party Parliamentary Group on Dementia (2013) *Dementia Does Not Discriminate: The Experiences of Black, Asian and Minority Ethnic Communities*. London: APPG.

⁵⁰ Botsford, J. and Harrison Denning, K. (2015) *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley Publishing.

⁵¹ Ahmed, A., Mohammed, S. and Egal, U. (2016) *Dementia and Diverse Communities*. In A. Ahmed and R. Rogers (eds) *Working with Marginalised Groups: From Policy to Practice*. London: Palgrave.

⁵² Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

assessment⁵³ suggests that actions to address the health needs of BME groups in Salford need to consider how they can address both existing health needs and future trends in the BME population. As the BME population increases it will require the capacity of all services (e.g. memory clinics, smoking cessation services) to be more responsive to the needs (e.g. interpretation services) and expectations of these groups.

A request for data on the numbers of Salford residents from BME backgrounds with dementia, made in August 2016 to the Memory Assessment and Treatment Service (MATS) of the Greater Manchester West Mental Health NHS Foundation Trust revealed the following information, as displayed in table 2.

Table 2. Characteristics of BME people with dementia, August 2016 (N=65)

	N	(%)
Age groups (mean age: 76)		
40-49	1	(2%)
50-59	2	(3%)
60-69	9	(14%)
70-79	30	(46%)
80-89	20	(31%)
90-99	3	(5%)
Gender		
Male	24	(37%)
Female	41	(63%)
Ethnicity		
White - Irish	33	(51%)
White - Any other white background	15	(23%)
Asian/Asian British - Any other Asian background	3	(5%)
Asian/Asian British - Indian	4	(6%)
Black/Black British - African	2	(3%)
Black/Black British - Caribbean	2	(3%)
Mixed - White and Asian	1	(2%)
Mixed - White and Black Caribbean	1	(2%)
Mixed - Any other mixed background	1	(2%)
Other ethnic groups - Chinese	1	(2%)
Other ethnic groups - any other background	2	(3%)
Diagnosis		
Dementia in Alzheimer's Disease with Early Onset	3	(5%)
Dementia in Alzheimer's Disease with Late Onset	21	(32%)
Dementia in Alzheimer's Disease, Atypical or Mixed Type	30	(46%)
Dementia in Parkinson's Disease	2	(3%)
Multi-Infarct Dementia	4	(6%)
Vascular Dementia, Unspecified	2	(3%)
Unspecified Dementia	3	(5%)

Almost two thirds of those from BME backgrounds who have been referred to the MATS team in Salford were women and the average (mean) age was 76 years, which reflects national trends⁵⁴. The most common diagnosis was Dementia in Alzheimer's Disease, Atypical or Mixed Type (46%) and Alzheimer's Disease with Late Onset

⁵³ Riches, N. (2016) *Black and Minority Ethnic Groups Health Needs Assessment*. Salford: Salford City Council.

⁵⁴ Alzheimer's Society (2014). *Dementia 2014 Report Statistics* <https://www.alzheimers.org.uk/statistics>

(32%). However, the overall figures are low: only 65 cases were open in Salford. Correspondence with the MATS team revealed that people from BME backgrounds with dementia in Salford make up 4% or less of the caseload⁵⁵. Just over half (51%) of BME cases are White – Irish, and a further 23% come from other white backgrounds. It is also possible that the white other category does not pick up people with dementia from Salford's above average Jewish population due to there being no explicit Jewish option for Jewish on the ethnic-group question on NHS forms.

The numbers for the other ethnicities are very low, however. For example, while there were almost twice as many people from Black African backgrounds as White Irish backgrounds in Salford at the 2011 census (2.3% of the population compared to 1.2%), Black/Black British – African cases make up just 3% of all BME dementia cases in Salford. The proportion of Salford residents who identified as ethnically Indian (1.1%) and Chinese (1.1%) was only slightly lower at the 2011 census than those identifying as White Irish, yet they make up just 6% and 2% of the entire number of BME cases.

To aid our understanding of the MATS figures, we estimated BME dementia figures for Salford in two different ways. One way to estimate the numbers of people from BME backgrounds in Salford who have dementia is to take the estimates of the BME population of England and Wales who have dementia. It has been estimated that 25,000 people from BME backgrounds in England and Wales have dementia⁵⁶. Salford makes up 0.417% of the population of England and Wales, and 0.417% of 25,000 is 104 people⁵⁷. This is of course only a crude estimate, which does not take into account the fact that the proportion of the BME population in Salford is slightly lower than the national average (15.6% of the population in Salford, compared to 19.5% in England and Wales). However, the BME population of Salford is growing rapidly. The estimated number of people from BME backgrounds in England and Wales with dementia is also growing, and is expected to rise to 50,000 by 2026⁵⁸.

Another way to estimate numbers of people from BME backgrounds in Salford who have dementia is to use the national dementia prevalence rate of 0.77% or 1 out of every 130 people (approximately 800,000 people in the UK have dementia)⁵⁹. The BME population of Salford in 2011 was 31,698 people. If 1/130 of these people have dementia, then this would result in 244 people from BME backgrounds in Salford with dementia. On the one hand, this could be considered as a conservative estimate as the actual dementia prevalence rate in Salford is higher than the national average⁶⁰. On the other hand, however, it could be argued that the BME population of Salford is young and therefore less likely to have dementia. Still, the MATS open case load of 65 suggests a prevalence rate of 0.21% or approximately 1 out of every 476 people, which is around four times lower than estimates for the Salford as a whole.

Using either of these estimates suggests that the numbers of people from BME backgrounds in Salford is low. As discussed above, they are particularly low for ethnic groups other than White – Irish. In the qualitative research, which follows below, we sought to deepen our understanding through gathering the views of stakeholders and community members, and identifying barriers and facilitators to minority communities accessing dementia services/general health and social care related services in Salford.

⁵⁵ Email correspondence with the Greater Manchester West MATS team, August 2016.

⁵⁶ 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.

⁵⁷ Based on figures from the 2011 census.

⁵⁸ 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.

⁵⁹ House of Commons Library (2016). *Dementia: Policy, Services and Statistics Overview*
<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN07007>

⁶⁰ NHS England (2016). *Quality Outcomes Framework (QOF) Recorded Dementia Diagnoses*, August 2016
<http://content.digital.nhs.uk/qofdementia/1617>

11. Findings and analysis: community members

Participants were asked what they know about dementia and if they would recognise the symptoms in someone they know. They were also asked about where they would go for help, their knowledge of dementia services in Salford, and the experiences of people they know of these services. Other questions included how to raise awareness and how services can best respond to the needs of their community. Finally, they were asked about barriers and how these can be overcome. The findings are presented thematically under the following headings:

- (i) Knowledge and awareness of dementia
- (ii) Community views of dementia
- (iii) BME communities and access to services in Salford
- (iv) Barriers to accessing services
- (v) Policies and initiatives to promote inclusiveness
- (vi) Challenges to services being inclusive

(i) Knowledge and awareness of dementia

Community members were asked what they know about dementia. While the majority of participants indicated an intermediate level of knowledge, there were also responses from both ends of the spectrum (some had very little knowledge while others knew much more). For the majority of respondents, including recent immigrants and more established communities, a common thread was that their knowledge was improving.

At the more advanced end of the spectrum, one interviewee who came to Salford as an asylum seeker stated that:

I understand that it is a decline in mental health and it usually affects people, older people, and it affects their thinking, problem solving, the way they see things, their perception and it also affects their concentration. I also know that it affects like five per cent of people who are over 65 and it also, like 20 per cent of people who are over 85 are also affected by dementia. What else do I know? I also know that there have been some ways which the government have come up with to address dementia like the national dementia strategy which aims at early diagnosis of people who are going through dementia. I also understand that it's a problem in the country because it uses a lot of money like probably approximately, is it £15 billion a year? (Central African male participant no. 2)

Participants from the area's long-established Jewish community also displayed a good level of knowledge. For example, they were able to articulate the difficulties for sufferers in the development of the illness:

Most people it comes on very gradually, especially for short-term memory, but for some it can be more step-wise. That can be a problem because they can be just about coping and then they'll have a deterioration quickly and a level of forgetfulness. (Jewish female participant no. 6)

They were also keen to distinguish what made dementia distinct from other health conditions:

I think that dementia's one of the most amazing illnesses in the sense that the person who has it doesn't

know he's got it... The main people who tend to suffer mentally, not so much physically, mentally I think are the patients and relatives because the person himself or herself doesn't really know. (Jewish male participant no. 2)

Nearly everybody forgets things and maybe even forgets the word for something that they use a lot but I think it's mostly where you forget a whole train of events and it's almost like it's never happened. So, for example, you went to a party and you chatted to people and then afterwards you can't recollect the whole event. (Jewish female participant no. 6)

We all forget little things, not life threatening. So, you forgot to pick up the apples on the way home, so what? I think what you're experiencing is something quite more, quite detailed - not detailed - quite more... a greater intensity. (Jewish male participant no. 2)

Other participants generally indicated a sound understanding of dementia:

A mental health problem... that's my understanding. (North African male participant)

It can happen at any age... When I say that, I don't mean children. (British born female participant with African-Caribbean ancestry)

Several participants, however, indicated that they had only learned of dementia after arriving in Salford:

I never heard this word dementia. For me it's just you get older, you lost memory, it's normal, it's okay, but then when I came to Salford and got involved myself with different organisations, then I understood what the dementia is. Actually, the dementia itself is not a disease actually, it's caused by a lot of different diseases and the word dementia is just an umbrella name to it of those diseases. So, there might be like memory problem, there might be like symptoms, like confusion, personality change, depression, so they all make up dementia. So, that's what I heard and knew about dementia here in Salford. (South Asian male participant no. 1)

The CCG... They organised a community fair. That's when I started to know about dementia... Before I came to this country, I didn't know anything about dementia. Still, I have to say I don't know much about it, but I am aware of it. (Central African male participant no. 1)

I didn't know about dementia when I was back home. Now, when I look back I have relatives that really did have dementia, but because there wasn't much knowledge about it we didn't know. (Southern African female participant no. 1)

For participant who came to Salford after arriving in the UK as an asylum seeker five years ago, it was not clear whether he saw dementia as something distinct from general forgetfulness or a lack of mindfulness:

Sometimes you are holding something and you think it's your mobile. Then you see it's not your mobile, you've left it on the table. (South Asian male participant no. 2)

Responses from young asylum seekers and refugees indicated less knowledge, however, including the misconception that dementia could be temporary:

It's only if you've got stress... Or if you're addicted or something. (South Asian male participant no. 3)

I've heard about domestic violence, but that's - is it not similar? (South Asian female participant no. 2)

A woman with young children who has been in Salford for around five years said:

We didn't actually see any person like that and we didn't hear about it... and we don't know what the name of it is in our language. (South Asian female participant no. 1)

Identifying dementia

With the exception of those with little understanding of dementia, participants felt that they would be able to identify if someone they knew had dementia:

I would be able to have some kind of triggers which would be able to indicate if the person has got dementia... I don't know where they are, but, I think, if I need them, I might be able to find them on the Internet somewhere. (Central African male participant no. 1)

Sometimes they do things which are not age is appropriate. They have low mind in the brain, that's what

I'm saying, you can just recognise that. (Central African male participant no. 2)

I could pick some of those signs... If they are constantly forgetting things... Or when they are struggling to come up with solutions of simple things, to make decisions, or when you are talking to them they are far away, they are not concentrating. (Southern African female participant no. 1)

(ii) Community views of dementia

When it came to views of dementia within their communities, participants were less confident about levels of knowledge and understanding. Responses varied between, dementia being viewed simply as a part of the ageing process on the one hand, and being viewed negatively (i.e. a form of madness) on the other.

Dementia as part of the ageing process

Some participants suggested that in their communities, symptoms commonly associated with dementia such as memory loss and confusion were regarded as part of the aging process and as such were not always addressed:

In our culture, we think that it could happen because he's too old... So, in our culture, we feel it's some natural thing, there's no treatment for that... We believe there's no treatment for that, you can't help them, so we leave them as it is. (South Asian male participant no. 1)

We think we should accept loss of memory... we live with it. (West African male participant)

The flipside of this means that attitudes towards those with early-onset dementia could be negative:

I personally wouldn't say taboo. The taboo is if you're in your 40s or 50s. If I may say from an African perspective, they might say you are losing your mind, not have dementia, which can be claimed as a

normal process that is recognised or understood. (Second generation West African male participant)

A Jewish participant also suggested that, in general, with the Orthodox Jewish community *'somebody would have to really display features of dementia'* before it was identified that they had dementia (Jewish female participant no. 3).

Negative views of dementia

Some communities were familiar with the term dementia, using it as a loan word in their language:

When I speak to an Arab on the street and he talks about dementia, he'll say 'dementia', so people know what dementia is. (Middle Eastern male participant no. 1)

For other communities, though, the term used in their community to refer to people with dementia offered an insight into lack of knowledge and negative perceptions:

It's literally mad, now in the old age mad, that's it. (South Asian male participant no. 1)

Sometimes they describe it as some people who has problem in - mental problem or has problem in the brain. That's how they describe it. (Central African male participant no. 1)

Participants from the Chinese community noted that while in Hong Kong the term now used to describe dementia is relatively neutral, referring to reduced cognitive ability, the older term remains commonly used among the local Cantonese speaking community:

Lou nin ci daai zing, it's quite a bad name, you know? Lou nin means older people. First of all, you are really kind of stigmatized, like only older people get it and then it means disease kind of thing, so it doesn't say much really. It's quite a negative view... The group of Chinese in here, they really didn't hear of it. They still stick in dementia in the old, the negative form of name, yes. So unfortunately, they're still using it now. (Chinese female participant no. 1)

The participants felt that use of the term was linked to levels of knowledge about dementia among the local Chinese community:

It's just that Chinese still in this country... still don't know about dementia that much. They don't know what is happening, what does it mean like the life of dementia, how to take care of them and what is the diagnosis or what is the prognosis? That kind of thing, they are still very, very not clear. They don't know much about it. (Chinese female participant no. 1)

A participant from Central Africa felt that levels of knowledge were low and this was linked to negative views of dementia:

I would say, first of all, not many people know about it and not many people know how to define it. Even when it is defined, it is regarded, I have to say, as, it's not something that the community tend - the people who have got dementia tend to isolate themselves because they define themselves as not normal and they tend to feel that they are not regarded as part of our community. (Central African male participant no. 1)

A participant who had been in Salford for just a few months commented that:

Dementia in my country is not all that focused on... neither do we have very many. There are few who reach that age. (East African female participant)

(iii) BME communities and access to services in Salford

Participants felt that the first port of call for them or other community members would be the GP when faced with a potential dementia diagnosis. Beyond this, however, there was less certainty about how to access services:

The first call would be the GP. (Central African male participant no. 1)

I can say that the GP, also they can give me advice. (Central African male participant no. 2)

I just assume that if a member of my family or if I think myself, I can, having signs of dementia I was just thinking that I would see my GP and then the GP would probably signpost me to the relevant services. I've not received any information about dementia, although I think that leaflets are sometimes accessed in the local libraries and things. (Southern African female participant no. 1)

I'll be honest, I don't know... I only know of Black Dog [the campaign from Sane]. (Second generation West African male participant)

Positive experiences of services

One participant discussed how her family had accessed dementia services in Salford and had found an online forum particularly helpful:

When my gran was alive... She used to get really confused. She used to not sleep and go wandering into the night. So, my mum used to access them [GP services] for sort of safety. So, they came and they gave her some care buttons. (British born woman with African-Caribbean ancestry)

I think it was the Dementia Forum, my mum used them quite a lot, but they were online... sort of tips with how to deal with certain situations. (British born woman with African-Caribbean ancestry)

The Chinese participants emphasised the supportive role that family can make in navigating the early stages of access to dementia services:

I think [an] individual, if they find themselves struggling with their daily life activities, they will go to see the GP. Maybe if they don't have family to support them they will find it hard... Normally they can't do it by themselves. Normally the family members or the health worker is supporting them and then they make [a] referral. (Chinese female participant no. 2)

There was a sense dementia was becoming easier to identify due to changing attitudes towards dementia in the medical profession:

I feel years ago, that people telling, going to the doctor saying 'I'm quite forgetful' and the doctor says 'Oh, just let go' ... But recently, I think quite a lot have been diagnosed and it's easier to diagnose. (Chinese female participant no. 1)

Services not open to BME communities

Some participants felt that dementia services were not necessarily open to people from BME backgrounds in Salford, however:

I've got experience in the care industry and I've not seen so many black people in care homes. (Southern African female participant no. 2)

I used to visit care homes, like dementia care homes and you'll be surprised to know I've not seen a single person from an ethnic minority background in the care home. (South Asian male participant no. 1)

He sought to stress that while information is available, and organisations are providing essential services, word does not always reach people from black and ethnic minority backgrounds:

The people who are not in touch with those organisations are millions of miles away from this information and still I can tell you with this confidence that people still don't know what help is available out there in Salford. (South Asian male participant no. 1)

A similar point was made by another participant:

I have never seen the kind of literature which tells me if you suspect someone has got dementia or if someone, a member of the community approached me to say, 'Can I access the dementia diagnosis service?' or something like that, I wouldn't be able to tell. It's not widely publicised literature so it's not accessible. (Central African male respondent no. 1)

Culturally appropriate services

To some extent the Jewish community represented an exception in that culturally specific services are available in Salford and over the borders of neighbouring local authorities, including the Beenstock Home in Broughton, the Nicky Alliance Day Centre in Crumpsall (Manchester), and Heathlands Village, which is run by the Fed (Federation of Jewish Services), in Prestwich (Bury). The following conversation between Jewish focus group participants illustrates the services available:

Well, the first stop would be the GP and then they'd get a referral, wouldn't they? (Jewish female participant no. 3)

*In the Jewish community, you'd phone up the Fed, wouldn't you? (Jewish female participant no. 5)
I would say the Fed. (Jewish female participant no. 3)*

Later, 'The Nicky' (Nicky Alliance Centre) was suggested, before the same participant suggested another Jewish social care organisation:

Well there's one around the corner, The Beenstock Home and lots of those residents came to the home and they were fine. ... A lot of them are in their late 90s, early 100s, a lot of them have got dementia.

(Jewish female participant no. 3)

Still, even the participants from the Jewish community, who were otherwise well-informed, were unsure about mainstream services on offer in Salford, with one participant's question to the others ultimately being left unanswered:

Do you know if Salford CCG has any services or anything relating to dementia that dementia patients or their relatives could get involved in? (Jewish male participant no. 2)

(iv) Barriers to accessing services

When asked what the barriers were to their communities accessing dementia services, key themes emerging from participants' responses were language, the information gap, and culture, and the emphasis on these varied among respondents. Significantly, they perceived these as stemming from the ways in which services attempted to interact with their communities, and as such did not see the barriers as insurmountable. At the most fundamental level, one asylum seeker was not registered with a GP, and so she was signposted to sources of advice and support in the process of conducting the research.

The information gap

For others, however, it was more about bridging the information gap, which in many cases was seen as tied up with language and culture, but also networks which extend outside of their own community:

The multiple layers of barriers were noted by one participant:

I think there are quite a number of barriers. One of the things that could be the biggest barrier would be the stigma because of our cultural background we believe that, maybe we take dementia as something that people look down upon and people would think that a diagnosis of dementia would maybe lead them to go into care or to be controlled or something like that so people might not want a dementia diagnosis. Another barrier would be lack of knowledge of the services, of dementia services. Language could also be another barrier, like explaining things in their second language, doctors may not pick up what the patient is trying to say. (Southern African female participant no. 1)

The problem is some of our communities, or some other members, they don't have where they can get support if they have those issues. They don't have a network of - no services provided. How they can get support from other services who can help them, those people, those issues. It's different from Africa because there's not too many support - there's not too many services who can support them, where they can get help from government or some other services. (Central African male participant no. 1)

We don't have this platform where the services can really connect directly with the people who might be, or families who might be beneficiaries. We don't feel that there is a connect there, these two stakeholders if you like, are connected and I feel they need to be connected in terms of those who provide the service and our communities. There is a big gap there. (Central African male participant no. 2)

The same participant went on to note the difficulties of overcoming this information gap, particularly as some older immigrants may not have IT skills in order to access information online:

A barrier is lack of information, and barrier of language, barrier of background, because some of the people, they are scared or they don't know how services works here because of information, because where they are coming from, maybe it was not easy to access some services because they don't have any information about how things work here. (Central African male participant no. 2)

One participant sought to stress that in the case of new immigrants the gap takes time even for educated, successful individuals with good English language skills to bridge due to needing to adjust to the new context and terminology:

People, when coming here, they don't have all the information. You know, they're educated, they're all in business, but the terminologies are different in different countries. (South Asian male participant)

Language barriers

Language barriers were noted, and along with cultural attitudes towards dementia were seen to be more important than networks within the Arab speaking community:

Language barriers, I would say. Definitely language barriers. To be honest, I think with a lot of elderly people maybe feeling isolated, but I'd say with this community that's probably not the case just because they're such large families, extended families, and they usually have a huge support network around them. ...cultural barriers maybe. I'm not speaking for all Arab-origin people but there is sort of a taboo around mental illness and dementia and that kind of thing, and disability, cultural taboos. That could possibly be something. (Second generation Middle Eastern participant)

For the Middle Eastern community, it was suggested that language was more important than cultural barriers due to obstacles that this created in terms of creating networks outside of the community and the associated information gap.

If there are any barriers, it'll be a language barrier. A language barrier or what would I say, people being unaware of the service. So, for example if there was - if a GP didn't refer them they wouldn't know so with it being a health matter people will - their first contact will be their GP. If their GPs do not make them aware of the dementia services within Salford, they wouldn't know. (Middle Eastern male participant no. 1)

I think the engagement isn't the problem itself, I think the unawareness of the service and - because if people knew about the service, they would engage... Most of the community members are very, struggling in terms of accessing information because of language barriers, cultural barriers, so their self-confidence. When somebody comes from a foreign country into Britain, it's not easy to connect yourself. (Middle Eastern male participant no. 1)

The same participant pointed out that language was seen as a particular issue for older community members:

If we say look at the 65-year-olds and above in our community, they will be people with very little English so if they didn't have members of their families supporting them to tell them about the service, they wouldn't know, because when they go to the GP sometimes, they need an interpreter. (Middle Eastern male participant no. 1)

This was also an issue for a young South Asian participant:

They [parents] don't speak English as much as we do. So, if there isn't any interpreter in the surgery, or the pharmacy, then we have to go with them, and this is the kind of thing they need. (South Asian male respondent no. 3)

Interestingly, the Chinese participants did not see language as a particular barrier:

I would say the language barrier, only when they are looking for support. That's the barrier. It's not how to make diagnosis or how to explore the diagnosis. (Chinese female respondent no. 2)

Financial barriers

The financial costs of care were seen as a barrier, however:

I think finance is a main issue. So, for example if you are living with your parents and the house belongs to your parents and you have to sell the house then you go to the nursing home. (Chinese female respondent no. 2)

For one participant who arrived in the UK as an asylum seeker and now has refugee status, financial considerations were viewed as a barrier much earlier in the process of diagnosing dementia:

Whenever you want to access a GP, you have to call in the morning. I don't think they take into consideration that people might not even have money in their credit to call so access is difficult because of the funding cuts and all these austerity measures and the privatisation. (Central African male respondent no. 1)

Other NHS barriers

Others also saw barriers in the way that GP practices and the NHS operate:

Make it easier, not complicated to make an appointment with the doctor... The prices are going up for the medications, prescriptions. (North African male participant)

Two weeks... it's a long time to wait if you're sick. (South Asian female participant no. 3)

The cultural appropriateness of diagnostic tools was seen as an issue by the Chinese participants:

Some are not relevant question for older people like what's the capital of - you know, I'm not bothered. What's the name of the Prime Minister? If they don't watch the news, they probably never knew what the prime minister's name was. They can tell them the Chinese but not the English probably, I don't know. So quite a few, no, it's funny. I went with a patient to actually the Chinese doctor doing the mini memory test and he said, 'What is the president of the United States? Oh, this is not a relevant question.' She [the doctor] actually said it. (Chinese female participant no. 2)

Lack of culturally appropriate support

Again, the availability of culturally appropriate care is seen as an issue.

The whole pattern of care or the whole pattern of support in a nursing home is not Chinese style, I think.
(Chinese female participant no. 2)

While family is seen as a strong source of care for people with dementia, particularly in light of the stigma that can be associated with dementia, it is not to the exclusion of other sources of support:

Traditionally we try to take care of our family members when anything happened so it's strong, the family bond is strong. (Chinese female participant no. 1)

The stigma attached to people with dementia, I have come across quite a few carers and they will just say he just is walking slowly, he is just a little bit forgetful, he's not got dementia. Chinese have negative thoughts of dementia. So, he doesn't want to be labelled but if you asked them, 'Yes, do you want any nurse support?' They welcome any support, they really, really struggle and they really are crying for help, yes. (Chinese female participant no. 2)

It's the family members who take all those responsibilities to look after the elderly. Maybe it is because of the culture or maybe they don't know where to get the support. (South Asian male participant)

Jewish focus group participants saw cultural barriers in the sense of the emphasis on family care. However, this was again interpreted as a necessity rather than a free choice.

It's the sort of illness where you can at the beginning look after. So, you can look after them and the Jewish community tend to keep it in the family, don't they? They tend to look after their own family.
(Jewish female participant no. 6)

When it gets down to the end and they need full-time care in. They say it also takes a toll on the family sadly, so by then they need care. It's not a case of they don't want to be offered it. (Jewish male participant no. 2)

I think if people can afford it, they try and get a carer into their home if they can. (Jewish female participant no. 6)

Also, expressed a preference for culturally specific services:

Because if you don't fit into Beenstock and you don't fit into Heathlands, you have to go to one of the other homes which... It's difficult to organise Kosher food and prayers and... So, that is a big hole.
(Jewish female participant no. 2)

While they saw barriers, which impacted upon the extent of access to dementia services by the Jewish community, it is interesting to note that when asked about barriers, they responded by making suggestions for what they could do to overcome these. Also, they have extensive structures in place to help bridge any cultural barriers, such as financial services to defer payments that would otherwise be required on the Sabbath (for example, when needing to use a taxi to leave hospital), as well as community first responders to support with emergency health needs.

(v) Policies and initiatives to promote inclusiveness

When asked about what kinds of policies and initiatives can help to promote inclusiveness, there was little in the way of current practices that community members sought to recommend beyond the use of the Fed's Heathlands Village as a model for other care homes. They did have a number of suggestions for how dementia services could be improved from the perspective of Salford's BME communities. These related to making services more accessible, furthering efforts to disseminate information and engage, and creating training and volunteering opportunities for Salford's diverse communities.

Efforts to disseminate information and engage

The availability of interpretation services was seen as an issue, but not the only answer, as one participant emphasised:

The language barrier is one of the problems. I think as a community we're not exactly - not able to cover all the languages but we know which languages would be appropriate to translate this material into. One other thing is to get a written leaflet or something like that, which will tell them about what dementia is and what the triggers are, and how people can become friendly to those who experience dementia. I think it is very important how we make the information accessible. (Central African male participant no. 1)

Some other people might not be able to read and write. Another thing is about audio, things people can listen to. (Central African male participant no. 1)

While leaflets were also discussed by other participants, this was seen as just one strategy of getting information out and making services more accessible, as one participant stated:

I'm thinking especially of people who attend groups. Maybe some sessions to talk more about dementia would help, and maybe some, if GPs could have leaflets which are available in different languages. (Southern African female participant no. 1)

Not all participants advocated such approaches, however, with one participant commenting that:

Mostly, we don't read newsletters, we just bin them. (South Asian male participant no. 2)

A female South Asian participant responded that:

It might be through the radio because elderly people listen to the radio and watch the TV, basic channels. So, giving them information on these types of media could help, because nobody can go door-to-door to tell them these types of things are happening and you need to come to us or the GP... Elderly people might read the newspapers. (South Asian male participant no. 1)

Another participant suggested that there was a need to:

Educate people through advertising... outside on the billboards. (Southern African male participant)

Moving beyond passive one-way communication was seen as essential by another participant:

Leafleting definitely no. No, because you know, there are thousands of leaflets sent, but I think some practical thing, that we need to tell them that, maybe show some video about dementia, give the training, tell them what the dementia is. So, it's all about face-to-face at the local groups, so that will be something that will help, but if you're talking about like websites, leafleting and everything or emails, that's not going to help. (South Asian male participant no. 1)

Others also sought to emphasise the importance of getting people together to discuss dementia so that they can interact with peers in a comfortable environment:

It's about doing some workshops and trying to organise some event and talk about it. (Central African male participant no. 1)

The older people like the gathering... and the elderly people can say they have this problem and I'm getting treatment and the others will listen. (South Asian male participant no. 2)

You need to put on some entertainment, something to attract them. So many elderly people go to the gathering to make themselves relaxed. So, it might be helpful if we can make it interesting for them. (Female South Asian participant no. 1)

Support for bringing people together to learn about dementia was shared by the Chinese participants, who thought that this would be particularly beneficial for older and first generation immigrants:

We should organise more of this kind of awareness talk which is quite, you know, relevant to the particular group and also quite beneficial to them... The second generations they are quite good with English, then they are able to go online, to Google, to find out more about service and stuff like that but for the older generation, the older group and the first generation in this country, first generation of Chinese migrants to here, I think they still don't know a lot about outside services, what are available, that kind of thing. So again, awareness talk, you know like or like service. (Chinese female participant no. 1)

One of the Middle Eastern participants also suggested an awareness event, and emphasised that in order to be most effective, it should be held where the actual community is based:

I don't know, I think maybe it'd be worth in the future if planned and funded, to have a dementia awareness day where Arabic speakers come and deliver - or somebody comes and delivers, with Arabic interpreters. (Middle Eastern male participant no. 1)

One thing about our community, they don't travel unless it's important. (Middle Eastern male participant no. 1)

The support of participants, many of whom are actively involved in community organisations, suggests that there are existing networks that can be utilised to promote awareness raising events:

I think if you go through the churches, you can educate the congregation about the availability of NHS

services. (Second generation West African male participant)

Another respondent suggested ways of making this as inclusive as possible:

We need to actually work with the faith groups, especially with the - you know, we have got the Muslims, Christians, Jews, so it is important to work with the faith groups, because that is something that we can access and is easy. One more thing, it'll be good with the school children, because the parents who can't speak English, but if we actually engage with the children, then they will go back and will talk to the parents, so it will be helpful. (Central African male participant no. 1)

Creating training and volunteering opportunities

Training was seen as a key way of moving beyond one-way communication:

I think we, as the community, need training to actually know the signs of dementia and how we can in our family and friends, if we see someone with those signs, to have that thing. So, the most important thing is to have that training with the BME community and I've not seen any around dementia with the BME community, so how we can detect that someone has got the dementia or is suffering from dementia. (South Asian male participant no. 1)

One participant sought to go one step further by creating volunteering opportunities, which she saw as a way of helping to change attitudes in the BME communities:

Maybe inviting people from ethnic minorities to volunteer in services so that by volunteering one will come to understand that it's like any other thing, it's like having high blood pressure. There's no stigma attached to it, it's only a condition. (Southern African female participant no. 1)

In recognising that this is an issue which goes beyond those professionals with specialist knowledge of dementia, a participant echoed the idea of Dementia Friends. More specifically, he suggested that there is a need to support a wider range of people to improve their knowledge of dementia and reach out to all parts of the community:

It doesn't matter where they work or you know, whether it's in a supermarket or it's a GP or it's a receptionist, need to have some base information about dementia and talk to people about that and in that way, we'll be able to reach more and more people. Rather than just the people who work with the dementia and that's it... it's the duty of all of us together, to reach to all of them and give that information that's available. (South Asian male participant no. 1)

Accessible services

One participant suggested that improving the visibility of centres offering dementia services could also help to change attitudes:

I think if they are easily accessible, maybe locally, and like dental clinics, we know that these are dental clinics but with dementia services we don't know even if we've got a hospital, we don't know probably where they are located. Maybe they could have signs, bigger signs for people to know that this is a dementia centre and people are free to walk in and ask questions. (Southern African female participant no. 1)

Another idea for promoting engagement and the accessibility of services, this time suggested by a young refugee from South Asia was a mobile health service:

We can have a mobile service, for example... like two times or three times a week in different places, like Asda car park, and there's the charity places... Well, they're already there, but we need like more of those. (South Asian female participant no. 4)

Learning from best practices

A Jewish participant emphasised that the good practices of the Fed's Heathlands Village could also be learned from and capitalised on:

I wonder if the CCG use Heathlands as a model for the non-Jewish sector as well because they probably could use it as a training hub. (Jewish female participant no. 6)

Another participant suggested more use of services which were previously available through the Horizon Centre, a GP practice specialising in the treatment of asylum seekers:

It is very important is to engage the BME communities and to know the barriers, because for example, if we are giving training or talking to people in English, there are many who are newcomers here, as I said, that you tell them what the dementia is. So, you need a proper professional interpreter who can actually interpret the things rightly and demonstrate it, so that is the important thing, that there needs to be someone who can speak their own language and actually explain first what dementia is and then the treatment and other things available. (Central African male participant no. 1)

(vi) Challenges to services being inclusive

Some of the participants were aware of a number of limitations to making services more inclusive. In the discussions, they primarily emphasised the wider policy context, which shapes the way that services in Salford operate: austerity, immigration law, and ways in which GP practices work.

Austerity

A number of respondents felt that public sector cuts over recent years had a detrimental impact:

It's getting hard, because I've been working in different services, to do things when there's cutting of money by the government to different services. (Central African male participant no. 2)

English class - but they don't have those opportunities because the government has cut money. (Central African male participant no. 2)

A participant who came to the UK only in the last year after previously working as a health professional stated:

I'm uncomfortable in this country. I have had no support to learn English. (Middle Eastern male participant no. 2)

Another participant also felt that austerity was responsible for the closure of the Horizon Centre, leaving asylum

seekers facing difficulties when attempting to access mainstream health services:

Focussing mainly on asylum seekers, they live on £37 per week, which is £5 per day. It is very, very difficult if you are telling them to put credit on their phone. You can imagine how it's difficult for them to access GPs. Again, looking at severing cuts in services, in Salford we used to have what GP practice called the Horizon Centre. You probably know about this. It was a specialised GP practice in refugee and asylum seekers issues so again because of funding cuts, it doesn't exist anymore, so it is very, very difficult, I have to say. (Central African male participant no. 1)

Welfare conditionality

For some respondents, welfare conditionality was seen as a hindrance to their longer-term development and participation in British society:

In Europe - Germany, Sweden and others, anybody immigration... he goes to learn the language and after that he goes to the job centre. But this country is different, the first time you coming here... go to the job, look for job. I came here and after 20 days they cut the money. What did I do? ...Anybody coming here needs one year, two years to learn English, then no problem. After that I work anywhere. (North African male participant).

Changes to immigration law

A participant sought to stress that he felt that changes to immigration law to crackdown on illegal immigration and protect public services were also placing increased pressures on asylum seekers in Salford and adding further obstacles to those wishing to access health services:

The Immigration Bill 2015 affects directly our communities. It's going to affect our communities because people, the asylum seekers, won't be able to access health services. It means that to access their GP, the GP would have to ask you if are recognised as a refugee or not, so it's going to be even worse. I'm kind of a positive person but this is the reality on the ground. (Central African male participant no. 1)

Community members' views on dementia services

Overall the findings indicate varying levels of knowledge about dementia among Salford's BME communities. While the majority of participants indicated an intermediate level of knowledge, there were also responses from both ends of the spectrum (some had very little knowledge while others knew much more). The majority of respondents, including recent immigrants and more established communities, felt that their knowledge was improving, however. With the exception of those with little understanding of dementia, participants felt that they would be able to identify if someone they knew had dementia. Participants were less confident about levels of knowledge and understanding of dementia in their communities. On the one hand, some participants suggested that dementia is viewed negatively and even seen as madness, while on the other it may be simply regarded as part of the ageing process.

Participants were aware of some members of their communities accessing dementia services in Salford and there was a sense among some participants that dementia was being diagnosed more often due to changing attitudes towards dementia in the medical profession. The majority of participants indicated that there is a reliance on family care. Significantly, however, this was seen as arising, at least in part, due to a lack of suitable/affordable care or community members not being aware of services that are available. While participants were all active members of their communities, and therefore had some awareness of services, it

was felt that community members were much further away from services in terms of not knowing what is out there. The Jewish community represented an exception to some degree due to the wider availability of culturally specific services.

The barriers to BME communities accessing dementia services appear to be at the beginning of the Dementia Care Pathway in the sense that they relate to awareness. The main barrier can be seen to be the information gap, which is connected to language, culture and participation in social networks which extend outside of their own community, but also the ways in which services attempt to disseminate information and engage with BME communities (most participants had not seen any information about dementia services in Salford). Other barriers, which appear further down the dementia care pathway, include financial costs, NHS waiting times, and culturally appropriate diagnostic tools and care. Concerns about financial costs ranged from the costs of care on the one hand to prescription prices and telephone charges for a GP appointment on the other. Participants indicated that they did not see family care as a barrier to accessing services, due to the belief that community members would access services if they were aware of available and accessible culturally appropriate care.

Participants did not see the barriers as insurmountable and had a number of suggestions for how dementia services could be improved from the perspective of Salford's BME communities. These included improving the availability of interpretation services, and furthering efforts to disseminate information and engage with communities. Conducting awareness meetings, which draw on existing networks and peer knowledge of dementia were seen as a key way of improving awareness and understanding. They were also concerned with making services more accessible and person-centred rather than targeting particular groups. For example, improving the visibility of dementia centres, creating more training and volunteering opportunities for Salford's diverse communities, and in the vein of Dementia Friends, supporting a wider range of people to improve their knowledge of dementia and reach out to all parts of the community.

Participants saw the main challenges to promoting diversity and inclusiveness in dementia services in Salford as coming not from the communities themselves or local services, but rather the national policy context, including austerity and the associated impact on local services and the availability of English language classes, along with welfare conditionality and immigration law.

12. Findings and analysis: service providers/stakeholders

Stakeholders were asked to provide details about the nature and scope of their organisation's role: as indicated by the list above, some organisations are general health care providers, while others have a specific dementia care remit⁶¹. A small number of the organisations above are community based advice and information services, while others provide services for older people.

Participants were asked about the level of Salford BME communities' engagement with their services; their views on any barriers to access; whether their organisation had any specific policies or initiatives in place to address the needs of BME communities and make their services more inclusive; and to identify any examples of good practice locally, regionally and nationally. The findings are presented thematically under the following headings:

- (i) Awareness of the needs of BME communities in Salford

⁶¹ See appendix 1 for a summary of each organisation's remit.

- (ii) BME communities and access to services in Salford
- (iii) Barriers to accessing services
- (iv) Policies in place to address the needs of BME communities
- (v) Challenges to inclusive provision
- (vi) Examples of good practice
- (vii) Overcoming barriers and making services more accessible

(i) Awareness of the needs of BME communities in Salford

There was variability regarding the levels of knowledge and awareness of the needs of BME communities among stakeholders. Some were directly involved in delivering services to the community, others provided services in Salford which were used (often very infrequently) by BME communities, and others were involved in strategic decision making and resource allocation. However, some stakeholders who were involved in key roles in dementia services reported minimal experience of working with BME communities since they often did not access services.

One stakeholder commented:

The BME population is smaller and less established in Salford than in other areas of Greater Manchester (Health and Social Care Provider)

(ii) BME communities accessing and using services in Salford

Stakeholders were asked about whether BME communities accessed their services, and in the main across health and social care provision, older people's services, dementia services and more general/community services, it was suggested that take up was much lower than among the white population in Salford. From the responses received, it seems that the reasons put forward for such low take-up could be explained in two broad ways: first, the fact that Salford's population is predominantly White British; and second, stakeholders perceived a reluctance on behalf of BME communities to come forward to access primary health care in general and mental health dementia and care in particular.

Salford's population being predominantly White British

Several stakeholders noted that Salford's population was comprised of mainly White British people, and that people from BME communities were in a minority. Because of this some felt that the low numbers of BME communities accessing their services was proportionate to the wider population's ethnic constitution as the following statements illustrate:

I think honestly Salford is a predominantly white community and BME communities are a very small minority of the community makeup. (Dementia Services Provider)

What we know that the people who use our services are broadly representative of the general population of Salford. (Older People's Services Provider)

My impression of Salford is that it is quite a white area, quite working-class. I haven't actually come across people from any of the minority groups as yet. (Dementia Services Provider)

However, although low take-up of the service by BME communities is low, and some stakeholders felt that this

could be explained as reflecting reflects the ethnic constitution of Salford's population, there was also an acknowledgement from others that BME communities have in fact been under-represented in service use *as a proportion* of the wider population and not just reflected by low numbers using services:

At the moment, I'd say BME groups maybe have been under-represented so far in the people that we work with. (Older People's Services Provider)

Several stakeholders indicated that although they engaged with a range of different people in Salford that this was limited to members of the White British population, and that people from BME communities were not involved:

We work with lots of different groups...at the moment, I think, everybody is white British...so in Salford at the minute I don't think that we're reaching anybody from a BME community. (Older People's Services Provider)

Unfortunately, I don't have anyone from BME backgrounds involved in any of our projects. (Dementia Services Provider)

To be honest... our patients would be White British predominantly ... so I've got very limited experience of any other ethnic groups in that environment. (Health and Social Care Provider)

I haven't yet met someone from those groups in Salford. We take referrals from statutory organisations ...but also from charitable organisations As long as the person has a diagnosis and are living in the community, we can work with them. It wouldn't matter what group they were from. If they came to us, we'd work with them. (Dementia Services Provider)

One stakeholder indicated that they had experience of working with older adults from BME communities, and they stated that the numbers of such people were so very low that they would be able to recall their names:

I would probably say five or six in the last year, in the last eight months or so.... Obviously, I won't give you the names, but I could almost give you the names of those patients because you can remember them because, you know, you might nurse them slightly differently in terms of their cultural beliefs, their families and you adjust and adapt slightly different, for their beliefs. (Health and Social Care Provider)

From the excerpt above, it is apparent that there is an awareness of the need for person centred and culturally sensitive care when providing services to people from a BME background. However, this view was not shared by all participants in the research, as some suggested that treating everyone 'the same' was appropriate and represented equal treatment through service delivery:

I'll just go into the care homes and notice that we might have people from the Black and Ethnic Minority; it's not something that you think about much really to be honest... When I go into the care homes obviously, there are people from black and ethnic minorities there so I'll just see them as I would see any other person with dementia if there was a problem. (Health and Social Care Provider)

Reluctance to access health and dementia care and support

Health and Social Care Providers tended to report that Salford's BME communities did come forward to use their services, but that in the main people presented much later with health problems than the white population as the following excerpts suggest:

It's always been difficult to encourage people from BME communities to present, to have screening, cervical screening, flu vaccinations, childhood immunisations and, you know, the NHS health checks. It's

been always difficult to encourage people. They present when they're ill but it's usually physical illnesses. (Health and Social Care Provider)

Well I think that reflects the presentation with other illnesses as well. You know, although I say they do present when they're ill, they have to be really ill before they present. You know, they tend to manage within their own families for as long as possible, until crisis point and that's when we get involved. (Health and Social Care Provider)

Given the reluctance of people from BME communities to access health care and support services for more general health matters, it was not surprising to find that there was a greater reluctance to come forward for dementia treatment, care and support, as the comments from several stakeholders indicate.

We had quite a large Asian population and the problem was that we never saw the ladies. We saw the chaps very rarely. We saw quite a few of the children, but we didn't see many of the adults and they certainly didn't come with memory problems. They would perhaps come, ladies would come with gynae problems if they did come, and the chaps, obviously they are higher incidents of diabetes and cardiovascular diseases, so they would come for that. But no, very rarely did they present with memory problems. (Health and Social Care Provider)

No, I just wish I had more to tell you really, that I could say that we were getting people in because obviously, everybody's welcome and I don't know what the answer. (Dementia Services Provider)

Another Dementia Services Provider suggested that the location of services may influence the low take-up of services by Salford's BME communities:

The geography of services may have impact as no Dementia Support Groups run in east Salford, which is more diverse area. (Dementia Services Provider)

Some stakeholders suggested that less visible BME communities were absent, although other minority community members did come forward to use services.

Some Polish and Ukrainian people have come forward to use our services but no BME. (Older People's Services Provider)

(iii) Barriers to BME communities accessing services

A number of barriers to BME communities accessing services were identified by stakeholders, which can be summarised as follows: stigma, language and culture; lack of knowledge about services and challenges in navigating systems; a historical lack of engagement and representation of BME communities in Salford; assumptions that care is provided by family; lack of confidence in services; due to dementia; while a small number of stakeholders suggested that there were no barriers.

Stigma, language and culture

Several stakeholders suggested that language barriers, cultural factors and stigma surrounding dementia could prevent people from BME communities coming forward and accessing services. However, many also acknowledged that they did not know for certain how such barriers operated:

If the older people are, say, I'm just guessing, from the Yemeni community, for example, English may not be the first language. They might have been here 30 years but this is what I'm told, anyway. I don't know the facts of it. (Health and Social Care Provider)

It could be language it could be culture...but I have no experience or evidence to back this up. Maybe stigma is also an issue. (Dementia Services Provider)

The impression that I've got from speaking to other practitioners is that sometimes there can be a stigma from some communities, I think particularly within the South Asian community, about people living with dementia and so I assume that that could prevent people from accessing the service. It's maybe kept a bit more within the family. (Dementia Services Provider)

There may be language barriers where people's first language isn't English. (Health and Social Care Provider)

Stakeholders also indicated that the barriers to BME communities accessing general health services were even more apparent in mental health and dementia services:

As far as mental health is concerned, it's very rare to find people presenting either themselves or their families presenting for them, which we assume is a cultural issue, that there perhaps is some cultural problem with accepting mental health issues and possibly dementia. That's the assumption and we do try. (Health and Social Care Provider)

There is a stigma I think, culturally around mental health issues generally so there is a further issue for people accepting that they or a family member may have dementia. (Health and Social Care Provider)

Lack of knowledge of services and challenges in navigating systems

Almost all of the stakeholders who participated in the research felt that there was a lack of knowledge among Salford's BME population about the services they provided, and that this operated as a significant barrier to accessing these. Additionally, some stakeholders suggested that people from BME communities may not be familiar with navigating (often complicated) systems and that this would act as a further barrier:

I think people not knowing about us, an ignorance of our services within those communities because it's not something they've come across or been told about. (Health and Social Care Provider)

You do find people don't know about us still amongst the general population. People know about Age UK and they know about Alzheimer's because they're nationwide. (Dementia Services Provider)

People don't know what their rights are. (Health and Social Care Provider)

I suppose you've got Dementia Friends, you've got Dementia Champions, you've got a lot of stuff...there's so much stuff going on around dementia - actually you wouldn't know where to go because there's too much of it in some ways and everything's got a different name and none of it belongs to one umbrella. I don't have dementia, but I still find it very confusing as to who does what and where I should go to - so I should think somebody living with it or somebody who's living with somebody with dementia might actually find it quite confusing if they were on their own, to know how to go about things anyway. (Health and Social Care Provider)

The same respondent then went on to suggest that people from BME communities experience additional difficulties in accessing service, compounded by language:

Then if you add the added value that English isn't your first language then actually how do you navigate your way around the system? What is the system? (Health and Social Care Provider)

An Older People's Services Provider explained that as well as a lack of knowledge about available services,

Promoting diversity and inclusiveness in dementia services in Salford

entitlements and how to approach and engage with services, there was also often a reluctance to identify as a care-giver:

People don't often think of themselves as carers, you just look after your partner. To label yourself a carer is a huge step and shifts the dynamic in a relationship. In certain communities there is perhaps a more defined expectation about what people do for one another, they may be even less likely to see themselves this way 'why am I not just his wife'? There is also a lack of understanding of dementia, where do people go for diagnosis. (Older People's Services Provider)

This was felt to be a significant issue for BME communities where there could be cultural expectations around care-giving:

I think just from my own personal experience, I think the carer burden is greatest in certain BME communities because the elders are revered and if the elders are causing problems, behavioural problems, it's very, very hard to deal with that person because that person is the elder and what they say is law, if you like. (Health and Social Care Provider)

It was also acknowledged by one stakeholder that awareness of dementia among BME communities may also act as a barrier to accessing services:

An individual may not think of visiting GP as dementia is not a recognised as a problem in their community. For example, in one or two communities there is no word for 'dementia' so no popular understanding. (Health and Social Care Provider)

Historical lack of engagement and representation of BME communities in Salford

Several stakeholders felt that a legacy of lack of engagement with and representation of BME communities in health and social care services has contributed to the current situation where people from these communities do not access services in a proportionate number:

I think in general that our services aren't reaching those groups in Salford...most of the people I've worked with have been white and middle class, people who have tended to engage and come forward [and are] already active in the community. (Dementia Services Provider)

It was felt that there was a need for BME communities to be represented on patient panels, forums etc in order to articulate the needs of such communities:

There is a general lack of representation from people from BME communities when a lot of the local discussions about these kind of issues and the forums when and where they happen. Maybe people from BME communities will be less likely to engage with some of the forums. It's like maybe their voice and their understanding would be not properly heard. (Health and Social Care Provider)

The lack of BME representation on boards is the problem (Health and Social Care Provider)

Nobody in the dementia champions groups is from a BME background. (Health and Social Care Provider)

It was also suggested that the geographical location of services may act as a barrier to access:

I think one of the barriers might be that we're not operating currently in the areas where people live (Older Person's Service Provider)

Assumptions that care is provided by the family

A number of stakeholders suggested that people from BME communities did not come forward to use services as care was provided by the family:

So maybe they don't need the mainstream services. (Health and Social Care Provider)

They say there are not many people who are admitted to the care homes...I mean I think that is a cultural thing as well isn't it that a lot of families do care for one another and not always admit the relative to a care home. (Health and Social Care Provider)

There might be a cultural aspect where families would not ask outside organisations for support or assistance. (Health and Social Care Provider)

I think BME communities tend to have their own structures and systems which they live within. (Dementia Services Provider)

I think it's to do with the different cultural norms and ways of dealing with things... You tend to think sometimes that the people get a better deal because of an emphasis on family and life and community. (Dementia Services Provider)

I think I'm a little bit handicapped here by not having worked in a very diverse setting...some groups take the view that they will look after their own. (Health and Social Care Provider)

Lack of confidence in services

A number of stakeholders suggested that people from BME communities in Salford may not come forward to use services due to not believing that such services were able to meet their needs, or due to a lack of trust:

I think probably I would say one of the biggest might be the reluctance of some of those groups to approach an organisation that they may feel don't know much about them and their culture. (Health and Social Care Provider)

Although they may approach or be invited to approach other organisations, they may not feel comfortable in doing that because they may feel the workers they encounter wouldn't know much about what they actually are needing. (Health and Social Care Provider)

Trust; trust is a major barrier. (Health and Social Care Provider)

Due to dementia

Some stakeholders indicated that living with dementia could potentially act as a barrier to people using services since there could be a denial of the symptoms, or the condition could impact on people's ability to engage:

It's just like a lack of acknowledgement, maybe a denial but there may be a bit of a burying of the problems that are associated with dementia. (Health and Social Care Provider)

It's very difficult to get people living with dementia to come along to the work that we're doing because, as you'll know, people living with dementia can often lose confidence in being outside. Carers can lose confidence with getting people living with dementia outside. (Dementia Services Provider)

No barriers

Some providers commented that although take up by of their services by BME communities was very low, that there were no significant barriers preventing access:

I don't know what else there would be really [to make services more accessible]. I mean we're open to anybody in Salford. (Dementia Services Provider)

There are no barriers here because we would be offering people, each person who's registered with the practice the same sort of interventions if you like. There might be some language barriers that a person has got dementia and they may not be able to... Sometimes people who previously spoke English sometimes revert back to a different language again so that might be a barrier but we do have an interpreter service so we would look into everything to enable people to access the services fairly. (Health and Social Care Provider)

If we were approached by someone from those communities or they were signposted to us or we heard about them, perhaps they were referred to us by another organisation, we would have no problem in treating them the same as anybody else who came to [us]. (Dementia Services Provider)

In the excerpt above, the stakeholder indicates that a willingness to engage and offer services but the onus appears to be on BME communities themselves to make the approach and to be accessible and visible.

(iv) Policies and initiatives in place to address the needs of BME communities

Stakeholders were asked about whether their organisations had policies in place to specifically meet the needs of BME communities, and whether they had these in place in relation to dementia. All reported that they had general equality and diversity policies in place:

We've got our policy and diversity policy that's across the organisation but we don't have anything specifically linked to dementia, no. (Health and Social Care Provider)

We have ... policies and they are just the general ones. What they really are, they're council policies that have just been adapted slightly but not much. They're virtually the same. So we don't have an individual policy for this centre; as the other day centres wouldn't have. (Older People's Services Provider)

Well, we have a policy to address the Equalities Act and accessibility so, again, obviously ... So all staff have training on equality, diversity and inclusion. (Dementia Services Provider)

Yes. We have policies relating to social inclusion and dealing with diversity amongst our staff and the people that we work with. We've got a fairly diverse staff group really in terms of probably at least a third of the staff come from BME communities. (Health and Social Care Provider)

We positively engage with equality and diversity training for all staff and volunteers. (Dementia Services Provider)

We have general equality and diversity policies. (Dementia Services Provider)

(v) Good practice identified

Stakeholders were asked to identify any areas of good practice or initiatives that had been developed to promote inclusion of BME communities in dementia services. These are summarised below:

I think Together Dementia Support would really stand out for me in the way that they are very inclusive.

They do reach a range of backgrounds and that, I would say, socio-economic, race, gender. So they're really good. I don't know. I think possibly with the church but the service that they do is very warm and welcoming. They're trusted in that area. They're known in that area. As far as I know, they work in quite a small area which I think helps you to become known. (Health and Social Care Provider)

Good practice example 1: Together Dementia Support

Together Dementia Support was set up at the end of August 2014, it is a not-for-profit Community Interest Company offering support and therapeutic activities for people living with dementia, their care givers and supporters in Manchester.

They provide high quality activity and support groups to help people with dementia to maintain skills and hobbies, and to enable both them and their carers to make friends and maintain wellbeing.

They run weekly groups including: friendship and activity groups in Moss Side and Didsbury; an evening carers' group in Chorlton; a walk and talk group in Whalley Range. They also run monthly groups including: gospel singing in Moss Side; and a 'fabulous forgetful friends influencing group' in various locations.

I know the Jewish population has The Fed and, from what I've heard about The Fed, it's a fantastic organisation. They've got fantastic resources and a residential place. (Health and Social Care Provider)

Good practice example 2: Heathlands Village

Heathlands Village is a care home just beyond Salford's border in Prestwich, Bury, which is run by the Fed (Federation of Jewish Services). With 120 residents, plus accommodation for supported independent living, it offers residential, nursing, respite, dementia and end-of-life care, as well as day services and is also home to the Fed's adult social care services, which support people living in the community. Over 70% of people that they look after at Heathlands Village have some degree of dementia⁶². Due to its location, a significant proportion of the people they look after come from Salford.

Heathlands Village is run in a way which supports Jewish people's religious and cultural needs. There is an on-site synagogue, the Sabbath and Jewish festivals are observed, and all food on-site is kosher. Residents are free to decide to what extent they observe Jewish religious practices.

To respond to the needs of residents with dementia, they have increased staffing ratios, encouraged all staff to undertake dementia training (including virtual dementia training), and redesigned the buildings and outdoor areas (which now include two sensory gardens). When undertaking activities for people with dementia, such as music therapy, they use music and materials which reflect the Jewish culture.

⁶² The Fed (2017). *Dementia Care* <http://www.thefed.org.uk/services/heathlands-village/dementia-care/>

There are other areas of the country where there may be a specific worker whose job it is to develop links with minority groups. I did meet someone on a training course who said they were looking to develop something called Side by Side, which is like a befriending plus but for BME groups, so they were definitely looking at targeting that type of group.
(Dementia Services Provider)

Good practice example 3: Side by Side⁶³

Side by Side volunteers are matched carefully with a person with dementia in their community and they provide agreed support and companionship to that person at regular intervals. A person might be accompanied to their local park or cinema; supported to start a new leisure activity; or to just stay at home and have a chat. It might be that support is also provided over the phone if that is what the person wants. Volunteers are supported by a Side by Side Manager and will report to them regularly about their volunteering and to ensure that the person with dementia is happy and safe too.

In Gloucestershire Side by Side offers a respite and befriending service for those whose lives are affected by dementia. Side by side can offer support to both the person with dementia and the care giver - for the person with dementia, respite / befriending can help to alleviate social isolation, while for the care giver / family it can provide a much-needed break.

It was noted by some stakeholders that Salford Health Matters⁶⁴ and Salford Together⁶⁵ embodied the principles of good practice and inclusion, for example through the use of interpreters and that this improved access for BME communities.

(vi) Challenges to providing inclusive services

As reported above, there are a number of barriers which influence BME communities coming forward to access health and dementia care and support services, some of these barriers could be explained in terms of organisational barriers, and other in relation to a lack of knowledge of dementia and available services among BME communities. Stakeholders were asked to identify any challenges for their organisations providing inclusive services and these can be broadly described as 'structural': in terms of wider contextual issues, including funding and resource constraints and a historical lack of evidence and information sharing; and a lack of organisational and individual knowledge of how best to meet the needs of Salford's BME communities.

Funding/resource constraints

Stakeholders indicated that limited funding - particularly in the current climate where third sector organisations have to bid for funds - is a significant barrier to providing inclusive services. There appeared to be a recognition of what needed to be done to achieve this, but funding and resource constraints prevented it:

We do work quite hard to try and address that but obviously we've got limited funding... we would really love to have more people from BME communities living with dementia accessing our services.
(Dementia Services Provider)

I think in the current situation where we have to bid for funding, we have to prioritise, I suppose, as to

⁶³ We found examples of Side by Side initiatives operated by the Alzheimer's Society and also as a social enterprise.

⁶⁴ A social enterprise delivering health care in areas of identified need.

⁶⁵ A federation of GP practices and partner organisations.

where we do what is planned. I know we have business development officers who do a lot of work with the local authorities and quite how that translates into a service for BME groups, I'm not sure... A lot of our work is funded by voluntary income and you can imagine it's spread quite thinly across the country to try and provide something for as many people as possible. (Dementia Services Provider)

I think that is something that, we probably should be doing...to go out to maybe harder-to-reach communities, maybe identify where there may be a grouping of minority groups that we could approach. We're happy to do that, it's not a problem, but I'm only one person. I'm the only person who works in Salford so you can imagine taking referrals, doing home visits, doing events, all the administration involved with that, and then trying to do development work as well, [and]... I only work four days a week. (Dementia Services Provider)

Evidence and lack of Information sharing

Some stakeholders felt that the way people's ethnicity was recorded, a lack of evidence of demand for services from BME communities, compounded by a lack of information sharing among health and social care and dementia services, also presented challenges to inclusiveness:

When anybody registers, nowadays - it didn't used to be like this but you have to provide either your passport or proof of address and then there is a national form you fill in, in order to register, which asks for your ethnic origin. You do get some quite odd answers because people sometimes are not that keen on letting you know and it's not obviously what they put sometimes. (Health and Social Care Provider)

Obviously sharing of data is very sensitive and there's a lot of governance around sharing of data and confidentiality, and you have to assume - I mean, with the Salford integrated record, when patients do register, if they've not already agreed to have a certain amount of their information shared, if they decline, then that's it. You can't share any of their information with anybody. (Health and Social Care Provider)

There is a lack of monitoring and sharing data which is a problem. (Health and Social Care Provider)

There are plenty of passionate people but they are all working in isolation (Health and Social Care Provider)

Lack of knowledge of how to meet BME communities' needs

Several stakeholders stated that they had very little experience of working with BME communities, and did not feel confident or knowledgeable about the needs of diverse populations. A lack of representation of people from Salford's BME communities was also considered to be problematic:

I think personally, because I've not had a lot of experience with BME communities, it might not be... I might not understand at the beginning what they were looking for or why they perhaps didn't access us in the past, but you can only learn that by experience, by working with more people. (Dementia Services Provider)

However, we don't know about BME communities or if there are any active links. For example, in Eccles there is a Yemeni population but we don't know who to contact or how to engage with them. (Health and Social Care Provider)

Staff tend to be mainly white European and may not have any knowledge of BME communities. (Health and Social Care Provider)

I suppose I don't think people have thought about how we support people [from BME communities] ... to

be able to help people that maybe living with dementia. (Dementia Services Provider)

(vii) Overcoming barriers and making services more accessible

Stakeholders were asked to identify ways to overcome the barriers to service provision and increase accessibility and inclusiveness. A number of suggestions were put forward: the need to increase knowledge of other cultures; increasing outreach and engagement activities; evidencing need; raising awareness of dementia among BME communities; and increasing BME representation.

Increasing knowledge of other cultures

Increasing knowledge of other cultures was felt to be necessary by almost all participating stakeholders. This included: understanding how BME communities understood and experienced dementia which would involve training for GPs and health and social care staff; greater representation of BME staff; and investing time into developing appropriate services.

I think there's a tendency to look at dementia according to a biomedical model but I suppose it's got its biomedical elements obviously [but] how we engage with and support people who have dementia is largely a socio-cultural thing really and that if you're going to make any progress in dealing with that you've got to understand and try and work with the socio-cultural dynamics otherwise you're not addressing the things that people are really bothered about or understand. I suppose the predominant way of looking at it is in terms of a loss of capabilities in terms of abilities to self-care, abilities to relate and communicate with other people. How that plays out is massively effected by the cultural environment. (Dementia Services Provider)

There needs to be training for GPs as gatekeepers of services and there is also a need for GPs to come from different ethnic and cultural backgrounds. (Health and Social Care Provider)

People are also worried about how dementia is assessed, we need to know how dementia assessments should be conducted for people from BME communities. (Health and Social Care Provider)

I think it fits into a bit of a broader understanding because nobody just fits into a simple box. Even if you say from the non-BME community it's pretty diverse and maybe engaging with it but doing the BME work helps to appreciate there are different ways of looking at things and different ways of approaching in terms of there has to be some kind of flexibility built in to the general approach to dealing with these things which isn't always that welcome because it probably makes it harder to do things. (Health and Social Care Provider)

I think you can develop workable solutions to things where they may present challenges but it's quite an organic process and you can't just come in with a basic methodology that might work elsewhere and just assume that it's going to work in a particular environment enabled with a particular group of people without doing a lot of the hard spade work. (Health and Social Care Provider)

Increasing outreach and engagement activities

Stakeholders suggested that increasing outreach and engagement activities was necessary if services were to be more inclusive. This was thought to involve developing better links with different communities, having a strategic and flexible approach to engagement, targeting services to the areas where BME communities are located and 'reaching out' to communities rather than expecting them to come forward to access services. It was also felt that much more needed to be done to publicise services and there was a need for BME representation:

We need an engagement plan. We need a strategy to engage with BME communities in Salford. (Health

and Social Care Provider)

I think probably ... what we need to do is identify any meeting places for the groups and maybe offer to go and talk to them...I would like to think that we could do a bit of outreach work with those communities, but whether it's going to be possible, I don't know. I don't know. (Dementia Services Provider)

We need to go out to communities rather than expecting them to come to us (Older People's Services Provider)

I think ... for each community, if they have a group of influential people within that community, if you can tap into them and explain the reasons why things need to be done in a certain way or ask them what is their view of the best way of getting these things done, then we're better armed at how to deal with it. You know, we can't assume that just how we go about things is the right way all the time. So I think that's one thing that we need to do, is find out in each community which are the influential people, who do those people listen to? (Health and Social Care Provider)

I think it is something that we do acknowledge as an organisation that we are not reaching minority cultures enough...we need to invest the time and prioritise those relationships. (Dementia Services Provider)

Maybe an understanding of how to work with the community in such a way that it's not either them doing everything themselves or we're doing it for them; finding some ways in the middle where we can harness the potential of the things that we can bring to the table and they can do the same and find like a workable mix between them. (Health and Social Care Provider)

I think we've got quite a good profile but when you speak to people for the first time, they say, 'I didn't know what you did' ... I think we still have quite a bit of way to go to get ourselves more known and what we actually do. (Dementia Services Provider)

We need to have representation on patient panels. (Health and Social Care Provider)

Evidencing need

Some stakeholders suggested that it was necessary to identify levels of need in order to effect appropriate levels of provision for Salford's BME communities experiencing dementia.

There needs to be some evidence of need, how many people have a diagnosis and from what community so we can tailor services and meet this demand. (Health and Social Care Provider)

We need to know how many people have a diagnosis, where they come from, where they live so we can ensure services meet need. (Health and Social Care Provider)

The starting point must be the hospitals – they should ask the right questions, for example who is going to look after you when you get home? Lack of identification is a missed opportunity, GPs and other health services should be asking these questions too. We still need to increase identification of who actually is a carer. (Older People's Services Provider)

We need stats and figures to establish a baseline and this needs to fit into the Joint health needs assessment. (Health and Social Care Provider)

Raising awareness of dementia among BME communities

Several stakeholders suggested that it was important to raise awareness of dementia among Salford's BME communities, as many people were not 'in the system' which meant that they would not receive care or support:

If you've been diagnosed with dementia you're in the system, aren't you? So, you're going to get information, you're going to get support, you're going to get signposted but actually to be diagnosed, so you've got to recognise that there might be something that needs to be diagnosed and for people, perhaps BME communities, it's not necessarily - because of the way BME communities tend to work in their community, it's just that's natural because they're getting elderly, they're getting forgetful. So actually, it's only really done in the education with the BME communities about what the signs of dementia are and how to support loved ones and what is available to help them, because otherwise they will just naturally manage it themselves. (Health and Social Care Provider)

Another challenge is the need for awareness raising in terms of dementia - how people interpret what is going on their perspective of the problem may be different. (Health and Social Care Provider)

Stakeholders' views on the needs of BME communities

Stakeholders' levels of awareness of needs of BME communities in Salford varied a good deal. Some had direct experience of delivering services to diverse communities, while others provided services in Salford which were very infrequently used by BME communities. Significantly, the majority of stakeholders who were involved in key roles in dementia services reported minimal experience of working with BME communities since they often did not access services.

In the main, take up of services - across health and social care provision, older people's services, dementia services and more general/community services - by BME communities was low. Stakeholders suggested that this was due to Salford's population is predominantly White British and a reluctance on behalf of BME communities to come forward to access primary health care in general and mental health dementia and care in particular. Some stakeholders acknowledged however, that low take up of services did not accurately reflect the demography of Salford's ethnic population since proportionately, take up from BME communities was low.

Health and Social Care Providers tended to report that Salford's BME communities did come forward to use their services, but that in the main people presented much later with health problems than the white population, and, it was not surprising to find therefore, that there was a greater reluctance to come forward for dementia treatment, care and support. A number of barriers to BME communities accessing services were identified by stakeholders, which can be summarised as: stigma, language and culture; lack of knowledge about services and challenges in navigating systems; a historical lack of engagement and representation of BME communities in Salford; assumptions that care is provided by family; lack of confidence in services; due to dementia; however, a small number of stakeholders suggested that there were no barriers.

Stakeholders indicated that their organisations had general equality and diversity policies in place, but that there was nothing specific in relation to dementia. Some identified specific initiatives which they deemed to be 'good practice', which could be built upon: Together Dementia Support; Heathlands Village; and Side by Side. A number of challenges for their organisations providing inclusive services. These can be broadly described as 'structural': in terms of wider contextual issues, including funding and resource constraints and a historical lack of evidence and information sharing; and a lack of organisational and individual knowledge of how best to meet the needs of Salford's BME communities.

Finally, stakeholders identified several ways to overcome the barriers to service provision and increase accessibility and inclusiveness: the need to increase knowledge of other cultures; increasing outreach and

engagement activities; evidencing need; raising awareness of dementia among BME communities; and increasing BME representation.

13. Conclusion

This project aimed to gather evidence to improve access to dementia services for Black and Minority Ethnic (BME) communities in Salford, increase carer identification and registration, and raise awareness of the needs of Salford's diverse communities; and to increase staff knowledge/develop evidence-based decision-making relating to minority communities who may access dementia services/general health and social care related services in Salford. It is clear from the data gathered from community members and from stakeholder organisations that a good deal of work needs to be done to increase awareness of dementia among Salford's diverse communities, and to increase awareness of the needs of such communities among health and social care, older people's services, and in particular, dementia services. The findings from this research project in the main bear out the literature and policy review: there are challenges in providing inclusive services due to lack of awareness, but significantly, in Salford, the main barrier appears to be at the start of the Dementia Care Pathway. Awareness and Identification of dementia are the two key areas which should form the basis of an engagement strategy since this is where there is a significant knowledge gap both on behalf of BME communities and in relation to service providers in Salford. For BME communities, the knowledge gap relates to language, culture and participation in social networks which extend outside of their own community. For service providers, this relates to the ways in which services attempt to disseminate information and engage with BME communities. Several stakeholders stated that they had very little experience of working with BME communities, and did not feel confident or knowledgeable about the needs of diverse populations.

Therefore, there is limited knowledge about dementia among Salford's BME communities, in terms of the condition itself and how to access services and support. Similarly, among stakeholder organisations, there are gaps in knowledge of how best to meet the needs of diverse communities and how to make services more accessible. There are some misconceptions about dementia among some BME communities, and there are also assumptions that care would usually be provided by family members. These issues work together and compound a situation whereby BME communities are reluctant to come forward for treatment, care and support, and service providers lack the confidence to appropriately 'reach out' to diverse populations.

Inevitably, increasing awareness of dementia and the identification (diagnosis) of BME community members with dementia will result in an increase in demand for services. It is important that culturally appropriate diagnostic tools are used and that person-centred culturally appropriate care is provided, as well as care-givers being given appropriate support. There is also still work to be done to ensure relevant services (including the memory clinic) have the capacity and expertise to accommodate increasing numbers of people from the BME community. It is clear from the data gathered during this research project however, that at this point, priority should be given to increasing the knowledge of dementia among Salford's BME communities and increasing the knowledge of other cultures and community needs among staff/service provider organisations.

Economic and Social Value

There is considerable economic and social value to making dementia services in Salford more inclusive and diverse. The table, below, estimates the cost of dementia care in Salford for the BME population. The estimates are based upon average annual costs of £32,250 per person, which is approximately £5,272.88 on healthcare costs, including diagnosis; £5,517.98 on publicly funded social care; £7,111.13 on privately funded social care;

and £14,255.48 on unpaid care⁶⁶. We have included estimates for three different scenarios: Scenario 1, the current case; Scenario 2, based upon Salford’s share of 25,000 people from BME backgrounds with dementia; Scenario 3, based upon Salford’s share of 50,000 people from BME backgrounds estimated to have dementia by 2026⁶⁷.

Table 3: Estimated annual costs of dementia care for Salford’s BME community

Costs	Scenario 1 (n 65)	Scenario 2 (n104)	Scenario 3 (n 208)
Healthcare costs, including diagnosis	£342,736.88	£548,379.00	£1,096,758.00
Social care (Publicly funded)	£358,668.38	£573,869.40	£1,147,738.80
Social care (Privately funded)	£462,223.13	£739,557.00	£1,479,114.00
Unpaid care	£924,655.88	£1,479,449.40	£2,958,898.80
Total	£2,096,250.00	£3,354,000.00	£6,708,000.00

Although these estimates are for illustrative purposes only, they show the significant costs shouldered by individuals and their families, along with the public sector. Given the low number of dementia cases among Salford’s BME population, there could be considerable numbers of people who are already bearing the costs of unpaid care. From the perspective of health and social services in Salford, there are considerable potential costs which may arise at the point at which families feel they are no longer able to cope and need to draw on support. By promoting more inclusive and diverse dementia services, some of these costs may be saved, however. One study has suggested that early diagnosis of dementia followed by information and support reduces outpatient costs by almost 30 percent⁶⁸. In the context of the UK, more conservative savings of 3.65% (including direct and indirect costs) have been reported after accounting for the costs of screening and treatment⁶⁹. Based upon this more conservative estimate, if early diagnosis was made in the cases of 100 people with dementia in Salford, this would represent total savings of £117,712.50.

More inclusive and diverse dementia services would also bring social benefits, relating to finding appropriate treatments and sources of support, and facilitating decision making about the future. These are related to the improved wellbeing of people with dementia, their care givers and families, but also to the wider community too, for example by increasing trust and belonging, and improved relationships⁷⁰. The financial proxy values attributed to these kinds of improvements are significant. For example, being able to obtain advice locally for the over 50s outside of London is worth £3,931 per person per year; Feeling belonging to a neighbourhood is worth £6,004; and Feeling in control of life is worth £15,734. If just ten people felt these improvements, it

⁶⁶ Prince, M. et al. (2014). *Dementia UK: Update*, 2nd edition. London: Alzheimer’s Society.

⁶⁷ 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.

⁶⁸ McCarten, J. R. et al. (2010). Changes in Outpatient Costs following Screening and Diagnosis of Cognitive Impairment. *Alzheimer’s & Dementia*, 6(4), e19.

⁶⁹ Getsios, D., et al., (2012) An Economic Evaluation of Early Assessment for Alzheimer’s Disease in the United Kingdom. *Alzheimer’s & Dementia*, 8(1), 22-30.

⁷⁰ See, for example HM Treasury, Public Service Transformation Network & New Economy (2014). *Supporting Public Service Transformation: Cost Benefit Analysis Guidance for Local Partnerships*. London: HM Treasury.

would therefore be worth £256,690⁷¹. This is before considering wider benefits such as increased employment opportunities for carers. Given the gap between known cases of dementia in Salford's BME communities and national estimates, we believe that there is potential to add considerable social value. There is therefore a strong case for investing in making dementia services in Salford more inclusive and diverse.

14. Recommendations

- There is a need provide education about dementia to Salford's BME communities as there is often a lack of insight from people living with dementia and their family members. The way this is delivered needs to be culturally appropriate both in terms of content and the way it is disseminated.
- There is an additional and related need to provide information and publicity about the availability of dementia services through a range of culturally appropriate media (for example, community radio stations and posters), to dispel myths and remove the stigma surrounding dementia.
- There is a need for increased awareness of the needs of BME communities for service providers, including gatekeepers (GPs) and other organisations.
- There is a need for staff training regarding how best to approach patients within Salford's diverse communities.
- Employing health and social care workers from BME backgrounds would also promote approachability of services.
- Health and social care organisations need to be present in community spaces to successfully engage with Salford's BME communities.
- Dementia Friends needs to extend to Salford's BME communities.
- There needs to be representation of BME community members on boards and committees relating to dementia.

⁷¹ HACT and Fujiwara, D. (2017) *Community Investment Values from the Social Value Bank*. London: HACT.

Appendix 1 - Participant organisations

Age UK Salford

An independent local charity, established almost 40 years ago, which aims to improve later life for older people in Salford through support, information and advice. Age UK Salford's Dementia Support Service (DSS) has been working with families, individuals and professionals since 1998. The service provides community-based advice, guidance and support to individuals with a diagnosis of dementia, and to their care givers and families.

Alzheimer's Society

This is a UK based care and research charity for people living with dementia and their care givers. Despite its name, it does not exclusively help people with Alzheimer's disease, but is open to people living with all forms of dementia (and their carers). It is a membership organisation whose central remit is to improve the quality of life of people living with dementia.

BME Health and Wellbeing (Rochdale)

This is a community group based in Rochdale, whose aim is to raise awareness of chronic health issues within the south Asian and black, minority and ethnic community in order to prevent serious illnesses and for better mental health, physical health and wellbeing. They work with experts and in partnership with health and social care professionals and commissioners, clinicians, community groups and academics.

City of Trees

City of Trees was established in the 1990s and is a movement which aims to reinvigorate Greater Manchester's landscape by transforming underused woodland and planting trees. Their remit is to involve communities in forestry and they work with a number of different groups and volunteers.

General Practice

General practice (GP) General practitioners (GPs) treat patients with a variety of common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological and social aspects of care.

GP 'in reach service' – GPs go into care homes rather than have patients come to their practice.

Greater Manchester West Mental Health NHS Trust

Greater Manchester West Mental Health NHS Foundation Trust provides mental health services across Greater Manchester as well as medium and low secure mental health services to the wider North West region. It also provides mental health treatment, support and guidance for people of all ages living in Bolton, Salford and Trafford.

Healthwatch

An organisation that must exist by law, the role of Healthwatch is to ensure that local health and social care services and the local decision makers take account of the experiences of local people when planning and delivering care.

Humphrey Booth Resource Centre

The Humphrey Booth Resource Centre supports people with dementia and their carers living in Salford. The centre hosts a range of day services, carer support groups and acts as a venue for local community support groups.

Inspiring Communities Together

Inspiring Communities Together is a Charitable Incorporated Organisation (CIO) operating in Charlestown and Lower Kersal. The Organisation operates as a community anchor for the neighbourhood alongside delivery of services across Salford and beyond. ICT has office and delivery space within the Innovation Forum working alongside another Community organisation called People's Voice Media. The organisation operates through a consultation (our governance document) and has a membership of local residents and organisations who all want to make a difference to the neighbourhood.

Pennine Acute Hospitals NHS Trust

NHS Trust for *hospital* sites across the North East of Greater Manchester.

Public Health Specialist Registrar

Specialty registrars are public health doctors. They are just like registrars in other medical specialties.

Salford Carers Centre

Provides advice, information and support for carers in Salford. They have 1906 carers from BME communities registered with them (out of 6826, which is 27.9%). There are currently 60 carers of people with dementia registered from BME communities (as of September 2016).

Salford City Council

Salford City Council is the local authority of the City of Salford; one of ten metropolitan district councils in Greater Manchester. The City of Salford includes the more urban Central Salford, as well as Salford West, which includes the towns of Eccles, Swinton and Pendlebury, Walkden, and Irlam. The Council plays a key role in the purchase and/or provision of local government services, including social services.

Salford Community and Voluntary Services (CVS)

Salford CVS is the city-wide infrastructure organisation for the voluntary, community and social enterprise sector; providing specialist information, advice, development support and opportunities.

Salford Dementia Champions

Supported by Salford City Council and the Clinical Commissioning Group, Salford Dementia Champions group plays a key role in making sure that the views, experiences and interests of people with dementia and their care givers are heard and acted upon to improve dementia service delivery for health and social care in Salford. The group aims to strengthen links with all the GPs practices across Salford become representatives on Patient Participation Groups.

Salford Forum for Refugees and People Seeking Asylum

Shares information and raises awareness on issues affecting members' lives such as immigration, race hate crime, and local services. The organisation holds regular meetings along with community events promoting diversity and contributing to community cohesion. They also provide refugee awareness training to mainstream service providers, schools and local community groups.

Salford Health Matters

A community interest company investing in services to improve access to healthcare for Salford's residents. SHM works across 4 GP practices across Salford - Little Hulton, Littleton Road (Willow Tree), Gateway Eccles,

Promoting diversity and inclusiveness in dementia services in Salford

Homeless Service (Windsor Street). SHM is a Social Enterprise Company which is commissioned by Salford Clinical Commissioning group who commission on behalf of all GPs and enable all practices to know where to access services. SHM is an umbrella organisation that runs and supports the 4 practices with a central business unit to service them. SHM provides extra services for the 4 practices e.g. social prescribing.

Salford Healthy Communities

Helps prevent Long Term Conditions by involving local people in awareness raising and activities. They do this by bringing communities together into local teams, in order to harness their ideas, creativity, local knowledge and insight about what the 'problems' are and what the answers might be. The teams have regular meetings and receive training. The organisation also works with local service providers.

Salford Integrated Care Organisation (Salford Together)

Salford Together's aim is to help those who are well and healthy stay active so they stay healthier for longer and to support those who have care needs to improve their quality of life and independence with an overall focus on improving the health and wellbeing of all adults across the city.

Salford NHS Clinical Commissioning Group

Salford is made up of eight neighbourhoods:

- Claremont and Weaste
- East Salford
- Eccles
- Irlam and Cadishead
- Little Hulton and Walkden
- Ordsall and Langworthy
- Swinton and Worsley
- Boothstown

There are 45 GP practices across the city, all of which are members of Salford CCG and responsible for the local health services for 247,000 people.

Salford Royal NHS Foundation Trust

Runs Salford Royal Hospital, a large hospital in Pendleton. A range of dementia related services are offered at the Hospital.

Six Degrees

Six Degrees Social Enterprise is a Community Interest Company based in Salford that provides support for people who are experiencing mental health problems. Their social mission is to build resilient communities in which people with problems such as depression and anxiety are accepted, supported and equipped with skills to deal with the challenges they face.

The Fed

The Federation of Jewish Services, 'the Fed', is the leading social care charity for the Jewish community in Greater Manchester, providing support for people in their own homes or in residential care.

University of Salford Institute for Dementia

This is made up of a cluster of professions and disciplines at the University of Salford which are being brought to bear on the challenge of enabling positive and supportive environments for people living with dementia and for their care givers, including: the built environment; robotics, virtual reality, health and digital technologies; arts music and design; health and social care professions; social sciences

University of Salford students

The University of Salford has over 20,000 students from over 100 countries. Many of the students are from or reside in Salford, including students from a range of BME backgrounds.

Visible Outcomes

Visible Outcomes was established by three Salford residents who had moved from different countries and made Salford their home. The remit is supporting Salford's diverse communities through education and integration.

Wai Yin Society

A Manchester based community organisation, which supports, empowers and works in partnership with Chinese individuals and families. The Society aims to challenge all forms of discrimination and social exclusion through the provision of diverse and reactive services, delivered by a team of qualified social workers, nurses and other professionals. Services are currently offered to Chinese men and women and other ethnic minority groups, including Somali, Pakistani, Bangladeshi, Indian and many European nationalities.

Yemeni Community Association in Greater Manchester

The Yemeni Community Association (YCA) in Greater Manchester exists to help and support people whose family origins are in the Yemen or who hail from a BME background. Based in Eccles (Salford), the organisation provides access to education, training, welfare, leisure and recreation for Greater Manchester's 700 Yemeni families. The YCA also organises activities to preserve and promote the Yemeni language and culture.



Salford Institute for Dementia
University of Salford
The Crescent
Salford
Greater Manchester
M5 4WT

<http://www.salford.ac.uk/salford-institute-for-dementia>