The Alzheimer's Society Connecting Communities Project: External Evaluation

Final report

Jennifer Bray

Dr Simon Evans

Professor Dawn Brooker

September 2015

Acknowledgements

Address for correspondence

Association for Dementia Studies

University of Worcester

Henwick Grove

Worcester

WR2 6AJ

Tel: +44 (0) 1905 542296

Email: dementia@worc.ac.uk

Table of Contents

Executive Summary

Project background and overview

The number of people with dementia from Black, Asian and Minority Ethnic (BAME) communities is expected to increase at a greater rate than across the UK population as a whole. At the same time, people from this group are currently less likely to be diagnosed or are diagnosed at a more advanced stage of dementia. Raising awareness of dementia and risk factors that can be more common in some BAME communities could help to reduce the number of people with dementia from those communities in the future and reduce barriers to accessing services.

London is one of the most ethnically diverse cities in the world with 55% of its population being from BAME groups. The Alzheimer's Society's innovative 27-month pilot 'Connecting Communities' project began early 2013 and aimed to increase awareness of dementia amongst BAME communities. The project was initiated as an opportunity to engage with individual communities to address recognised issues including: a low awareness of dementia in BAME communities, low numbers of people accessing preventative dementia services (leading them to only engage with support at crisis points), and the diversity of local volunteers not being reflective of the demographic and target client base.

Under the guidance of a part-time Project Manager, four Community Development Officers were recruited to cover eight London boroughs: Croydon, Enfield, Hillingdon, Hounslow, Lambeth, Merton, Newham and Redbridge. Each Officer was responsible for two boroughs with their main responsibilities being to recruit and manage local volunteers and undertake community outreach activities such as developing community links and delivering awareness sessions.

The Association for Dementia Studies from the University of Worcester was commissioned to undertake an external evaluation of the project encompassing: questionnaires for community and dementia-related organisations; interviews with the Connecting Communities Project Manager and Community Development Officers at different stages in the project delivery; observations of dementia awareness sessions; focus groups with project stakeholders; and feedback from project volunteers.

Key evaluation findings

The Connecting Communities Project team undertook a significant amount of work starting in early 2013 in order to achieve the overall project aims and addressed a range of challenges. While volunteer recruitment has been difficult, around two thirds of the anticipated number of volunteers have been recruited across the

project – approximately 100 out of a revised target of 150. Subsequently, 350+ hours of volunteer training was delivered across more than 100 training sessions.

Volunteer involvement in the project, particularly through the development of appropriate translated resources to support dementia awareness activities, has helped to create a substantial legacy. The newly-designed 'What is dementia?' leaflet will be available in English, Chinese, Punjabi, Urdu, Hindi, Polish, French, Bengali, Guajarati, Turkish, Tamil and Somali, and will be a valuable resource for the Alzheimer's Society as a whole.

Although the Community Development Officers put significant effort into volunteer recruitment, the focus of the project shifted over time from actively recruiting and engaging volunteers to delivering awareness sessions and developing resources, both of which required a significant amount of preparatory work.

Over 540 dementia awareness sessions, talks and events have taken place, reaching 8,300+ people from BAME communities and greatly exceeding the original target. A total of more than 15,500 people have been reached by the project activities as a whole including 2,500+ professionals and more than 4,600 additional members of the general public, with the project having an even greater informal reach as people share their newly-gained knowledge. The BAME communities participating in the awareness sessions included: Afghan, African, Bangladeshi, Caribbean, Chinese, Greek, Indian, Somali, Tamil and Turkish, as well as further groups from Latin America, South Asia and the West Indies.

BAME communities have warmly-received and appreciated the awareness sessions. A key element of this success has been the flexibility to tailor sessions to the specific needs and preferences of the different communities. This has been supported by the use of an overarching presentation from which appropriate slides can be selected for each session. A toolkit currently being developed within the Connecting Communities Project will provide valuable guidance on working with BAME communities.

The resources developed by the project represent a significant step towards addressing the challenges of legacy and sustainability, and provide a strong platform from which to take this work forwards.

Project outcomes

This evaluation has explored the impact of the Connecting Communities Project in relation to four key outcomes.

Outcome 1: Engagement with BAME communities and community-specific dementia health care providers

33% of dementia services involved in the evaluation (n=6) saw an increase in the number of people from BAME communities engaging with them, and local Alzheimer's Society services also saw a change in their client base towards more people from BAME communities. While barriers remain with regards to people from BAME communities engaging with local services, the Connecting Communities Project has been increasing awareness of services and tackling the stigma that is often associated with dementia, with the overarching aim of facilitating access to services.

Outcome 2: Dialogue between BAME communities and the Alzheimer's Society and wider stakeholders

Community Development Officers have established good relationships with a variety of BAME community groups representing different faiths and backgrounds. Word of mouth recommendations within BAME communities have strengthened links and resulted in requests for dementia awareness sessions, both within the target boroughs and more widely across London. Community groups and volunteers have worked with the Connecting Communities Project team during the resource development phase, reinforcing connections between BAME communities and the Alzheimer's Society. In addition, the involvement of Community Development Officers in wider community events has helped to provide a stronger platform for raising dementia and BAME issues.

Outcome 3: Dementia awareness and knowledge of dementia care services in BAME communities

Over 8,300 people participated in dementia awareness sessions from a wide variety of BAME community including Afghan, African, Bangladeshi, Caribbean, Chinese, Greek, Indian, Latin American, Somali, South Asian, Tamil, Turkish and West Indian. Dementia awareness has increased amongst participating groups and the sessions have been a successful means of sharing key messages about dementia and local services.

Outcome 4: Understanding amongst professional groups of dementia-specific issues faced by BAME groups

The Connecting Communities Project has reached more than 2,500 professionals through its various dementia awareness activities. Dementia services have become more accessible and have an increasing awareness of issues faced by people from BAME backgrounds. Engagement with the Connecting Communities Project has also promoted recognition within the Alzheimer's Society of how important it is to focus on the needs of BAME communities. The range of work undertaken and the

relationships developed within the project have helped to increase appreciation of BAME issues amongst local commissioners across London, as evidenced by members of the project's Steering Group.

Recommendations for wider implementation of the Connecting Communities Project

- Disseminating the resources that are being developed is crucial to ensuring that the knowledge, experiences and learning from the pilot Connecting Communities Project are maximised;

- Providing an appropriate project structure in terms of location, management, supervision, data recording and reporting, and integration with local Alzheimer's Society teams are key facilitators for a successful project;

- Community Development Officer is a demanding and highly-skilled role that requires a mix of skills and experience including: dementia knowledge; a comprehensive understanding of the local area; the ability to develop and sustain relationships with a diverse range of local communities and groups. The time and effort required to successfully undertake this work should not be underestimated;

- Key elements of the Community Development Officers' workload include: establishing contact and engaging effectively with community groups; planning and delivery of tailored and interactive dementia awareness sessions; maintaining relationships following sessions; and working with volunteers;

- Dementia awareness sessions require careful planning that covers location, duration, group size, language requirements and resources. Appropriate follow-up to each session is an important part of ensuring the sustainability of the impact;

- Having a clear plan for the involvement of volunteers maximises the effectiveness of their input and reduces the potential for misunderstandings.

In conclusion

Through hard work and perseverance, the Connecting Communities Project Manager and the Community Development Officers have developed a strong knowledge base regarding ways to successfully and effectively engage with BAME community groups and work with volunteers from diverse backgrounds. The project has combined an overarching presentation and an experience-based toolkit to form a standard approach that remains flexible enough to be tailored to meet the individual needs of diverse community groups. Together with the recommendations regarding the underlying project management and support structure, this approach creates a robust platform on which further work can be developed.

Introduction

Black, Asian and Minority Ethnic communities and dementia

As the Black, Asian and Minority Ethnic (BAME) population ages over the coming years, the number of people with dementia from BAME communities is expected to increase at a greater rate than across the UK population as a whole. By 2051 3.8 million people from BAME groups will be aged 65+ compared to 532,000 in 2001[1]. In addition, risk factors such as diabetes, high blood pressure, stroke and heart disease which are associated with certain types of dementia are more common in some BAME communities.

People from BAME communities are less likely to receive a dementia diagnosis or are diagnosed at a more advanced stage than people from a White British background[2]. There is a need to establish support systems – with appropriately trained staff and volunteers – that will be able to meet the increasing demand while also provide support that is appropriate for BAME communities. This means appreciating the diversity within BAME communities and the barriers to accessing services, and addressing these at an individual level rather than adopting the same approach for all BAME groups.

At the same time, raising awareness of dementia and its risk factors amongst BAME populations and encouraging lifestyle changes could potentially have an impact on future numbers of people with dementia from BAME communities. It can also help to address stigmatisation of dementia and misconceptions commonly held about the disease which can be barriers to individuals and carers seeking help.

An important aspect of addressing the challenges faced by BAME communities is understanding what is meant by 'BAME'. For the purposes of this report, BAME is taken to include all of the categories from the 2011 census apart from White British. This list is provided for reference in Appendix 1.

Focusing on London

Within the UK the majority of people from BAME communities live in London, the Midlands and the North West of England[2]. As indicated by the 2011 census, 55% of London's population is from BAME groups, compared to 20% across England as a whole. London is one of the most ethnically diverse cities in the world. There is also considerable variation between boroughs with Newham and Brent both comprising

---

[1] House of Commons All-Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities.*
[2] Moriarty, J., Sharif, N. and Robinson, J. (2011) *Research Briefing 35: Black and minority ethnic people with dementia and their access to support and services*. Social Care Institute for Excellence.

over 80% of residents from BAME communities[3]. It is also expected that by 2021 26.7% of people aged 65+ will be from BAME groups[4]. In addition, in 2007 1.4% of London's population had dementia, a figure that is increasing[5].

Previous research has identified that in London there are *"many gaps in the provision of support for people from hard-to-reach groups, particularly from BME communities"*[6]. When addressing these gaps, London has a double challenge of providing services that take both dementia and BAME needs into account while also balancing the need to provide services where people are integrated regardless of background, against the need to provide separate services for separate groups.

Due to an increasing number of local and national initiatives, dementia is already high on the agenda within London, with many boroughs having their own dementia strategies. BAME issues are also being incorporated into some of this work as awareness increases, although this is a slower process. Examples of these initiatives are provided in Appendix 1.

Whilst such initiatives are encouraging, their existence creates a potentially confusing picture as multiple factors are involved and intertwined. In terms of the evaluation reported here, it makes it difficult to identify the key driver behind any changes that may be observed.

Project overview

The Alzheimer's Society was awarded funding by the Department of Health to undertake the Connecting Communities Project, an innovative 27-month pilot which began early 2013. The focus of the project was on engaging volunteers from BAME communities in order to design and deliver activities raising dementia awareness across eight London boroughs: Croydon, Enfield, Hillingdon, Hounslow, Lambeth, Merton, Newham and Redbridge. As outlined by the Alzheimer's Society[7], the project provides an opportunity to engage with individual communities and aims to address a number of recognised issues around BAME communities and dementia.

Aims and objectives

The main aims of the Connecting Communities Project were to increase awareness of dementia in BAME communities and consequently the numbers of people

---

[3] Kaye, N. (2013) *BME populations in London: Statistical analysis of the latest UK census*. Social Policy Research Centre, Middlesex University. Available from http://sprc.info/wp-content/uploads/2013/07/BME-communities-statistical-profile1.pdf (accessed 20/07/2015).
[4] Healthcare for London (2009) *Dementia needs assessment: Appendix 1*.
[5] Healthcare for London (2009) *Dementia Services Guide*.
[6] Sachrajda, A. (2011) *Dementia care in London*. Institute for Public Policy Research.
[7] Alzheimer's Society (2013). *Call for Expressions of Interest for Connecting Communities project: External Evaluation*

accessing preventative dementia services. The pilot project also aimed to involve local volunteers who are representative of the intended client groups.

In addition, the project has a set of targets including:

- At least 1,950 people from BAME communities:
    - To have received accessible information about dementia
    - To know how to get a diagnosis
    - To appreciate the benefits of getting a diagnosis
    - To be able to access local services
- To recruit 90 community engagement champions and 150 community engagement volunteers from BAME communities to champion dementia awareness in their communities;
- To develop a volunteering good practice toolkit to support volunteering opportunities that meet the diverse needs of BAME communities;
- BAME communities to have had the opportunity to influence local dementia and volunteering services;
- To develop a BAME commissioning toolkit that will be an online external resource to support the provision of BAME relevant dementia services;
- For each borough to report on the BAME communities and levels of dementia awareness in that area;
- To develop a contacts database for each borough that details target local organisations.

Planned project structure

Figure 1 highlights the planned structure for the Connecting Communities project, indicating which job roles are involved at what level.
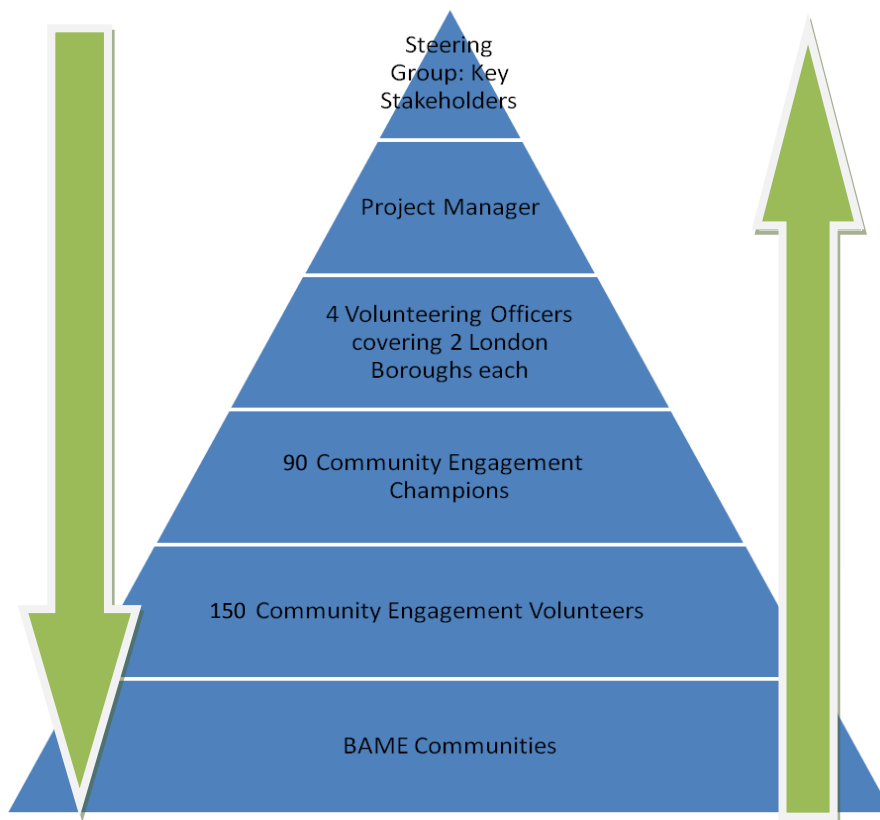
Figure 1: The Connecting Communities planned project structure

Borough information

Figure 2 shows the locations of the eight London boroughs that were the focus of the pilot Connecting Communities Project. The boroughs themselves are varied in terms of size, population, age profile and ethnic diversity. A brief profile of each borough can be found in Appendix 1. It should however be noted that obtaining consistent and current information about the different boroughs themselves can be challenging, and becomes even more difficult when trying to find more in-depth data regarding dementia and/or BAME communities. Information is often out of date, especially if it depends on census returns, and can be difficult to compare if data collection and recording is done differently depending on local processes and systems. Issues around a consistent definition of 'BAME' can also exacerbate this problem.

Figure 2: The borough locations

Pilot project evaluation

The evaluation of the Connecting Communities Project consisted of two parts:

1. An internal evaluation carried out by the Alzheimer's Society;
2. An external evaluation carried out by the Association for Dementia Studies (ADS) at the University of Worcester.

Internal evaluation

The core focus of the internal evaluation was to assess that the Connecting Communities Project was appropriately manages, had necessary financial controls in place, and was compliant with Alzheimer's Society internal procedures including risk assessments of project activities.

External evaluation

The external evaluation aimed to assess progress against the following project objectives:

Outcome 1: Increased engagement with BAME communities and community-specific dementia health care providers;

Outcome 2: Increased dialogue between BAME communities and the Alzheimer's Society and other stakeholders;

Outcome 3: Increased dementia awareness and knowledge of dementia care services in BAME communities;

Outcome 4: Increased understanding amongst professional groups of dementia-specific issues faced by BAME groups.

An interim annual report[8] by ADS described progress as of April 2014 and made recommendations regarding the direction of the remainder of the project. While it is not intended to repeat the findings from the progress report here, the 'Project summary and recommendations' section from it is provided for reference in Appendix 2. Relevant information from the report is incorporated into this final report when appropriate.

Ethical approval

The ADS evaluation team gained ethical approval from the ethics committee at the University of Worcester.

External evaluation methods

In order to evaluate progress against the four outcomes above, the evaluation applied a mixed methods approach which yielded both qualitative and quantitative data.

Questionnaires for organisations

To measure the impact of the Connecting Communities Project on local organisations, a questionnaire was devised for distribution at the start of the project, mid-way through the project and towards the end of project. The questionnaire was designed online using Survey Monkey©, and sent to community organisations that had received awareness sessions as part of the project. In addition, it was sent to dementia-related organisations as identified by ADS via the internet. Only organisations covering the eight target boroughs were included in the evaluation. The survey was distributed electronically to organisations via email, or as a hard copy in the post to organisations with only a postal address.

The main areas covered by the questionnaire were:

- Who uses the service, including how many people and what BAME backgrounds they are from;

---

[8] The Association for Dementia Studies (2014). *The Connecting Communities Project External Evaluation: Annual report covering May 2013 – April 2014.*

- If service use has changed over time (for dementia organisations only);
- Level of dementia knowledge within organisations and if it has changed following the awareness sessions (for community organisations only);
- Accessibility of services for people from a BAME background and for people living with dementia;
- Feedback on awareness sessions (for community organisations only).

The nature and volume of the quantitative data captured by the questionnaires meant that complex statistical analysis was not necessary and straightforward frequencies were sufficient. The questions that also captured qualitative information were analysed manually for common themes where appropriate. Due to relatively low response rates and the fact that some services covered multiple boroughs, it was not possible to obtain meaningful results for individual boroughs and consequently the responses were amalgamated and considered as a whole.

Semi-structured interviews

Approximately six months after the start of the project and again six months prior to the end, individual semi-structured interviews were carried out with the Project Manager and each of the four Volunteering Officers. The interviews were audio and video recorded after appropriate consent had been obtained from each participant. It should be noted that the Volunteering Officers' job title changed to Community Development Officer part-way through the project, and this new title will be used for the remainder of this report.

Additional telephone interviews were conducted with the four Community Development Officers between the two face-to-face interviews in order to monitor progress. These interviews also enabled the final views of one Community Development Officer to be captured prior to them leaving the project.

The aim of the interviews was to explore the barriers and facilitators within the project, covering the following areas:

- Working with volunteers
- Community engagement
- Delivering the awareness sessions
- Project support
- The overall structure and organisation of the project.

Thematic analysis was carried out manually and identified common themes across the interviews.

Session observations

Members of the external evaluation team attended seven awareness sessions in total, one run by each of the four Community Development Officers near the start of the project and one each by three of the Community Development Officers towards the end of the project. The sessions took place across the different boroughs with different BAME community groups in order to capture a range of experiences.

Observations were made in relation to a number of aspects of the sessions, including attendance, organisation and preparation by the Community Development Officers, any language issues encountered, session content and engagement with the groups. Where possible, the evaluation team members also spoke to individual attendees to capture their feedback including what they thought of the session, what they knew about dementia beforehand and what they might do with the information. In response to time and language constraints, the feedback was gathered in a 'vox pop' style, as represented by informal comments.

An observation template (see Appendix 3) was developed specifically for this project to enable the sessions to be rated against key points in a structured manner.

Stakeholder focus groups

The external evaluation team conducted two focus groups at the start of project Steering Group meetings to capture feedback from the key stakeholders in the project. Stakeholders who were unable to attend were invited to provide feedback via email.

The main areas covered were: what the group was hoping to achieve through the project; what they felt was working well; what could be changed or improved; the level of information they have received about the project; and potential barriers to the success of the project going forwards.

Volunteer feedback

Towards the end of the project a focus group was carried out with three volunteers to capture their thoughts and experiences of the project, together with an additional telephone interview with a fourth volunteer who was unable to attend the focus group.

External evaluation findings

This section presents the findings from the external evaluation of the project, illustrating what has worked well within the project, some of the challenges that have arisen and the learning that the Connecting Communities team have taken from their work as the project has evolved. As the findings from the different evaluation activities overlap in many cases, they have been amalgamated rather than being presented separately for each activity in order to avoid repetition.

The impact of being a pilot project

By its very nature, a pilot project is likely to be subject to change and face unforeseen challenges as it is attempting to implement new ideas from the ground up, and Connecting Communities is no exception. As commented by a member of the project's Steering Group, *"things may not turn out as you originally envisaged, but that's part of the learning […] not a flaw"*. In some cases, being a pilot has actually been beneficial for the project team as they have had more freedom to explore different avenues of work than they may otherwise have been allowed.

Project infrastructure

Planned versus practice

As seen previously in Figure 1, the planned project structure included two tiers of volunteers being managed by Volunteering Officers, and it was anticipated that the volunteers would be heavily involved in delivering awareness raising activities within BAME communities. In practice, the 90 Community Engagement Champions were re-classified as 'gatekeepers' who provided access to communities and organisations. They were not expected to become volunteers and were often community leaders or religious leaders. The volunteer target was therefore revised to the 150 Community Engagement Volunteers. It was also seen that the Community Development Officers delivered the majority of the dementia awareness sessions, rather than the volunteers.

In addition, as indicated previously, the project saw the departure of a Community Development Officer and the subsequent arrival of a new Community Development Officer in their place. This was used as a positive opportunity by the project team, and the borough allocation was altered in response to experiences of the targeted boroughs being too far apart. This will be expanded on later in this section.

The final development in terms of the project infrastructure was the recruitment of an Administrator. Administrative support was not available at the start of the project, but was quickly identified as being an important role within the team as they

were able to take some of the administration-related workload away from the Community Development Officers and the Project Manager. The part-time Administrator had a range of responsibilities including producing updates for the Steering Group using information drawn from the project's central monitoring database, co-authoring articles and working on resource translation.

Project management

The Project Manager for the Connecting Communities Project worked part-time, combining their role with work on other projects within the Alzheimer's Society. This created challenges for the Project Manager given the amount of work and size of team involved. Despite this, the Community Development Officers felt supported *"as much I think as I can be in this role"*, and reported that the Project Manager was always available when needed.

The dispersed nature of the project across several boroughs created specific challenges for project management. The team held monthly team meetings and regular supervision with the Project Manager, and the Community Development Officers welcomed being given a certain amount of space and freedom to try different ideas. However, they also suggested that the physical presence of a Project Manager would be appreciated at times. It should be noted that the Community Development Officers realised that their role *"would be a difficult role to manage"* and valued the work done by the Project Manager.

As the Community Development Officers did not have many chances to see the rest of the team outside of team meetings, peer support was very important to them. They received a lot of mutual support via email and learnt from each other's experiences, but *"there's only so much you can share via email"*. Being able to meet up in person was therefore appreciated, especially as the Community Development Officers worked on their own a lot due to the nature of the role.

Locations and teams

The pilot project focused on eight London boroughs as seen previously in Figure 2. The geographical location of these boroughs, combined with the initial pairings for each Community Development Officer (Table 1), presented some problems for the team due to the distances and travel time involved, with single visits often requiring the majority of a day's work. When there was a change of Community Development Officers the opportunity was taken to reallocate the boroughs, which brought borough pairings closer together.

Table 1: Borough allocations

Initial borough pairings	Revised borough pairings
Merton & Croydon	Merton & Croydon
Lambeth & Newham	Hounslow & Hillingdon
Hounslow & Redbridge	Newham & Redbridge
Enfield & Hillingdon	Enfield & Lambeth

In addition to the geographical challenges, the team felt that at times the project structure based on boroughs limited what they were able to do. Many community groups include people from more than one borough, and members will often travel a long way to take part in activities. In these circumstances, it was suggested that there would be advantages in adopting a community-based approach. As one Community Development Officer commented, *"you can't exclude any community groups because they're not in your specific postcode"*.

Due to the nature of the project, the Connecting Communities team were often dispersed across London and had limited face-to-face contact. This created challenges for communication and was exacerbated by the lack of a physical base for the whole project team.

On a practical level, having an office is useful in terms of storage and having a guaranteed desk. It also provides a central location to meet with people, which could potentially have helped to facilitate engagement with volunteers. An office base can also help to create a closer team and contribute towards a sense of belonging. One Community Development Officer commented that *"it can be quite a lonely job"*.

The approach adopted during the pilot project was for the Community Development Officers to use the local Alzheimer's Society offices within each borough, or a neighbouring borough where necessary. The Community Development Officers reported varying levels of satisfaction with this arrangement, partly depending on the individual offices in terms of capacity and the size of the team.

Some Community Development Officers reported a lack of integration into the local teams and little understanding about the Connecting Communities Project is and why it is important to focus on BAME communities. Some Community Development Officers felt that it was often down to them to try and establish relationships with the local staff teams, which was difficult when their work meant they were an infrequent presence in each office.

Where the arrangement did work, the Community Development Officers were able to do joint talks with other Alzheimer's Society staff. This can be beneficial as the local staff are likely to know more about the services available in their borough and have more detailed information than the Community Development Officer, but also gives them the opportunity to learn more about BAME issues and the Connecting Communities Project in general.

Resource development

One of the key activities undertaken as part of the Connecting Communities Project was the development of new Alzheimer's Society resources for dementia. While not a specific original aim of the project, it was quickly identified that the existing translated versions of information leaflets were not suitable due to some of the language used. The Connecting Communities team was well-placed to identify these issues and address them using their new community contacts.

A new leaflet on 'What is dementia?' was developed and refined with volunteers and community groups to ensure that it was relevant and appropriate for them. Gaining feedback on the translated versions from their target audiences helped to avoid repeating previous problems and guarantee that they are accurate.

While the development of the new resources has been important and a major benefit for the Alzheimer's Society as a whole, concerns were expressed regarding their long-term maintenance. This will need to be addressed within the Alzheimer's Society to ensure the resources are a lasting legacy of the Connecting Communities Project.

The unexpected need to redevelop the existing resources has meant that for a large part of the project the Connecting Communities team were unable to provide information leaflets in any language other than English. However, working with the community groups has made the Community Development Officers appreciate that while leaflets are good, they are not always the best approach. For example, if a group has low literacy rates many written resources will not be appropriate and something more visual would be required instead. The Community Development Officers were therefore considering options such as DVDs and podcasts as they encounter different needs within different groups.

In addition to resources used directly within the project, the Connecting Communities team had a certain amount of freedom to become involved in a wider variety of work due to being a pilot project. One example is working with Black African churches to develop a resource pack to make churches dementia-friendly. As a consequence of this work, the team has since been asked to develop a similar resource for mosques.

Information recording

The final aspect of the project structure is the ability to record information about the project. It is understood that this is currently done using a central online database where information is recorded about the awareness talks being delivered. This information can then be used for regular monitoring purposes to measure the numbers of people reached by the project.

While this has generally been sufficient, it was commented that it can be difficult sometimes for Community Development Officers to assess levels of project activity in each borough. It may therefore be a valuable exercise to reassess the data recorded to ensure that the database would be suitable to support the needs of any future Connecting Communities work.

The Volunteering Officer/Community Development Officer role

Development over time

As indicated previously, the Volunteering Officer job title changed to Community Development Officer part-way through the project because it was felt that the job description did not accurately reflect the role in practice. The original job description for the Volunteering Officer focused on *"co-ordination, recruitment, induction, support and training of volunteers"*[9] with no mention of delivering awareness sessions. The Community Development Officer job description is closer to what the role actually involves, but there is still no mention of delivering sessions. Instead it indicates that volunteers will have a bigger role with: *"volunteering roles that can support awareness raising, reduce stigma and promote independence working in partnership with local organisations"*[10].

Although the actual role has not changed in practice, the new title suggests that there is more of a focus on the community development aspect than on volunteer recruitment. The new title was also considered to be empowering by providing a more accurate reflection of what the Community Development Officers do and giving them more confidence when they attend meetings.

The Community Development Officers consider their jobs to have two main aspects:

1. The outreach work that focuses on developing community links and delivering awareness sessions;
2. Volunteer recruitment and management.

Each aspect was felt to be a substantial task in its own right, which created challenges for fulfilling the requirements of the job in a balanced way. One

---

[9] Alzheimer's Society (2013) *Volunteering Officer job description*.
[10] Alzheimer's Society (2014) *Dementia Community Development Officer job description*.

Community Development Officer reported that delivering a sufficient number of awareness sessions meant that "*I feel I'm not able to give my volunteers proper or full attention or support*".

Over time, the networking aspect of developing community links has evolved as the number and strength of contacts has increased. Additionally the need to develop suitable resources arose as described above, which led to volunteer recruitment becoming less of a priority for the Community Development Officers.

In some respects, how the Community Development Officers view their role differs from how the role was understood by the evaluation team based on the proposed project structure and intended outcomes. Firstly, it was thought that the volunteers would have more responsibility for delivering the awareness sessions rather than the vast majority being run by the Community Development Officers. Secondly, it was thought that there would be more work with professionals to improve their understanding of the issues faced by BAME communities, rather than the focus for the Community Development Officers being predominantly been on working with the community groups.

Working with professionals is important to ensure that when people from BAME communities do seek help the services are appropriate, accessible and equipped to meet their needs. This was recognised by one of the BAME community groups completing the final evaluation survey who commented that:

> "*more training is needed for GP's and frontline staff such as receptionists to have a greater understanding and grasp of cultural competency. Raising levels of awareness needs to be matched by an increase in support services*".

Although the Community Development Officers did not specifically target them, it was very encouraging that the project was still able to reach over 2,500 professionals through its various awareness raising activities.

Facilitators and barriers to the role
Training

The Community Development Officers all had relatively low levels of dementia-specific experience when they started in the role. This was not necessarily an issue for the project as dementia training was provided for the Community Development Officers as one of four key areas:

1. Standard training for professionals in any organisation – health and safety, lone working, data protection, equality and diversity;
2. Dementia-specific training – dementia awareness, person-centred care;
3. BAME-related training – cultural dimensions;

4. Working with people – effective facilitator, influencing others, organising events, volunteer management.

However, it was recognised that having some level of dementia knowledge could be beneficial for Community Development Officers as they would be more confident in their own knowledge more quickly, meaning that they would feel more comfortable going out and delivering awareness sessions and might require less support from the Project Manager.

Groundwork: "Get to know your area"

It was recognised that the importance of the initial groundwork and the time it required had been underestimated. Before being able to start engaging with different community groups, Community Development Officers need to know who those groups are. To do this, they need to know about their boroughs and the underlying demographics in detail. For example 60% of a borough may be South Asian, but they could actually be very young so the population aged 65+ may still be mostly White British.

It is also important for Community Development Officers to understand what sort of communities live in their boroughs and *"try and learn what it is that is unique with each group"* as *"there is diversity within the diverse community"*. If the Community Development Officers do not know about the people they are trying to reach out to, they cannot tailor their approach to meet their needs.

Teamwork

During the Connecting Communities Project the Community Development Officers made connections with a variety of people in many different roles. While some connections came about by accident, the importance of working with other people was recognised and appreciated, so having the time to develop key connections earlier in the project may have been beneficial.

For example, in one borough a Community Development Officer only found out about the local council's Liaison Officer through a chance conversation. They proved to be a good connection who became involved in a two-way learning process with the Alzheimer's Society. The Community Development Officer was able to teach the Liaison Officer about dementia and the work being done within the Connecting Communities Project, and in return the Liaison Officer ran an awareness session for a group of Alzheimer's Society staff to inform them about the travelling community.

Teamwork was also beneficial for Community Development Officers when they were able to deliver awareness-raising sessions in conjunction with a Dementia Adviser or Dementia Support Worker. It is good to have someone that you can *"go back and*

forth with" when presenting, and having someone with more knowledge of the Alzheimer's Society services and what is available within a borough can help to boost confidence.

Learning and experimenting

At the start of the project being able to shadow the Project Manager when they delivered awareness sessions was a useful experience for the Community Development Officers. It gave them the opportunity to become more comfortable and familiar with the sessions and see what was expected from them without the pressure of delivering the information themselves.

All of the Community Development Officers developed their own knowledge, confidence and presentation style as the project has progressed. They used each presentation as a learning experience to see what worked and how it could be changed in the future. Sharing their experiences with the other Community Development Officers through their peer support group was also beneficial.

It was appreciated that within the project the Community Development Officers were given the freedom to try out different ideas and approaches to see what worked in what situation, rather than having a rigid format to follow each time.

Qualities required by a Community Development Officer
"You have many fingers in many different pies!"

Our evaluation of the work of the Community Development Officers and the way in which the project has been structured has identified a range of skills and qualities required by a Community Development Officer, including:

- **Confident** – Community Development Officers need to be outgoing and sure of what they are doing;
- **Organised** – Keeping track of community group contacts, sessions delivered and volunteer engagement;
- **Flexible** – Both in terms of how they work and when they work as the role can include visiting community groups in the evening or at weekends if this is when they meet;
- **Adaptable** – Reacting to situations, thinking on their feet and being able to change plans and presentations on the fly;
- **Good at problem-solving** – The ability to think laterally and think outside the box to come up with different ideas and solutions depending on the situation;

- **Resilient** – Community Development Officers need to be determined and committed as they can often reach dead ends or face rejection when trying to contact groups. The role can also be exhausting at times;

- **Independent** – They need to be able to work by themselves and be self-motivating, using their own initiative;

- **Open-minded** – Being open to learning about different cultures, ethnicities and religious beliefs that may not align with their own personal beliefs.

Volunteers

Role within the project

The main challenge identified by our evaluation of the Connecting Communities Project has been the involvement of volunteers. While volunteers have been recruited thanks to significant effort from the project team, it is *"perhaps not to the types of roles that we initially imagined would be part of the project"*.

Despite the intention of the Connecting Communities Project to recruit volunteers at two distinct levels and involve them in designing and delivering awareness activities within their communities, in practice only Community Engagement Volunteers were recruited to the project with the Community Engagement Champion position being filled by less formal 'gatekeepers' who were not required to become official volunteers. There was also some confusion regarding the volunteer role. Comments from the project team indicated that it was not always clear what the intended role of the volunteers was, and what they would contribute to the project.

One of the issues identified in the interim annual report was that the volunteer role offered within the Connecting Communities Project is not a 'traditional' volunteer role and so may not match people's expectations. Compared to many volunteering roles, the input required from volunteers in the Connecting Communities project did not appear to have a regular pattern of time commitment. This meant that volunteers were often unavailable when the Community Development Officers needed them or were available on a day when they were not required. Some volunteers who *"wanted something a bit more regular"* were channelled to other services within the Alzheimer's Society such as dementia cafes. Even though these volunteers may no longer be part of the Connecting Communities Project, they are still helping to make Alzheimer's Society services in general more diverse and raising awareness of BAME issues more broadly.

How volunteers have been involved

Many volunteers did not want to be involved in awareness sessions or lacked the confidence to take on this role and *"would rather be in the background"*. The exceptions to this were often volunteers who had carried out similar activities in

previous jobs. Some also felt able to support a Community Development Officer during a session by helping to answer questions or translate where necessary, but this is still dependent on having the right levels of knowledge and confidence.

Volunteer case study: One volunteer has been working on the Connecting Communities Project for about a year and has found it very enjoyable as it has given them the chance to address some of the myths around dementia and meet people from a variety of backgrounds. Although they have found it challenging being a volunteer whilst working full-time and meeting family commitments, the Community Development Officer has been very supportive and encouraging.

The volunteer has given a talk to around 20 people and had a very positive experience with a very helpful and welcoming group. They enjoyed being able to reach out engage with communities and found it *"so rewarding"*.

One of the main activities where volunteers were involved was staffing information stands that are regularly held in local market places, libraries, hospitals and community hubs. In addition, volunteers have helped with:

- Designing and translating resources
- Promoting events and producing flyers
- Writing newsletters
- Administrative jobs
- Fundraising and collection tins
- Recruiting and co-ordinating other volunteers

Volunteer case study: One volunteer has strong IT skills and was able to make a template for flyers which can be used across the Connecting Communities Project. Although they do not deliver talks, the research, support work and event organisation undertaken by the volunteer has been incredibly valuable and they helped to identify a number of potential community contacts for their Community Development Officer.

The diversity of the volunteers has been beneficial for the Connecting Communities Project as they have been able to help the Community Development Officers by providing an insight into the attitudes and customs of their own communities, and the Community Development Officers appreciated their ability to help out with language issues.

Volunteer case study: One volunteer has been very active in their area, taking part in a number of events, cafes and information stalls as well as helping with resource translation. Due to their own background, the volunteer has provided a vital link enabling the Connecting Communities Project to reach women in local mosques. Without the knowledge and influence of the volunteer, this would have been much more difficult to achieve. Their language skills have also been very beneficial as they speak five Asian languages.

Recruitment

The original project target was to recruit 150 Community Engagement Volunteers. It is understood that approximately 100 volunteers have been recruited, which is an increase from the interim annual report when there were fewer than 50 volunteers. However, approximately one third of these volunteers are associated with one Community Development Officer. The volunteers form a diverse group as they are from different backgrounds and ethnicities and cover a broad age range, making them a valuable asset to the project.

Recruitment challenges

As mentioned previously, the Community Development Officers were not always clear about what role the volunteers would fulfil within the project, which contributed to some of the problems encountered regarding recruitment. To try and achieve recruitment targets the Community Development Officers made concerted efforts to advertise for volunteers online and within their boroughs, when in practice they did not always have sufficient work for them to do. As the project progressed, it was appreciated that to avoid potentially misleading volunteers the Community Development Officers *"need to have a volunteer opportunity before we recruit the volunteer for that opportunity"*.

Another challenge regarding volunteer recruitment was that it was a time-consuming process. Community Development Officers can invest a lot of time advertising the volunteer role then trying to follow-up potential volunteers who have expressed an interest, only to find that it does not actually result in successfully recruiting anyone. As one Community Development Officer summed it up, *"we take their details, you follow it up, you get nothing"*.

Even when volunteers had been recruited, issues were encountered around their training as there was a reliance on e-learning. For many volunteers this was difficult to complete due to a lack of desk space and difficulty accessing computers, and was less meaningful to some than face-to-face training where there is more engagement and interaction. Although face-to-face courses were offered by the Alzheimer's

Society they were mainly run in central London, making them difficult for many volunteers – especially those based in some of the outer boroughs – to attend due to significant travel times. Despite these challenges, over 350 hours of training was provided to volunteers across 100+ sessions.

When reflecting on the project, one suggestion made by the Project Manager was that a more successful approach may have been to provide specialist training for existing volunteers within the Alzheimer's Society and wider community groups rather than trying to recruit new volunteers to the Connecting Communities Project. The opportunity arose within the project to try this with an existing group of volunteers working for a Chinese community group, and it appeared to work well.

Change in focus

As the project has progressed there has been less emphasis on meeting volunteer targets, partly because of the need to focus on resource development as mentioned previously. The Community Development Officers have still continued to recruit volunteers, but not as pro-actively as they had been. Instead, there was a feeling that it is preferable to have fewer volunteers doing more substantial and meaningful work than *"lots and lots of volunteers doing little bits"*.

Management

The Community Development Officers felt that the amount of management required for the target number of volunteers was not fully appreciated at the start of the project, and in practice it would be unrealistic to expect one Community Development Officer to manage more than ten volunteers at a time. Even this number would still require a lot of effort, and it is *"difficult to manage that many volunteers whilst doing the community development side of things"*. Whilst managing volunteers is worthwhile, it is a time-consuming part of the Community Development Officer role.

It can be difficult for the Community Development Officers to maintain contact with their volunteers, especially when the Community Development Officers travel around a lot and are not able to provide an immediate response to emails. In addition, the short-term and ad-hoc nature of the volunteer involvement means that the Community Development Officers do not see them on a regular basis. This makes it more difficult to forge relationships with the volunteers, which can result in the Community Development Officers feeling *"quite removed"* from them. Ideally, the Community Development Officers would like volunteers who are more proactive and *"more practical about wanting to do something"*.

The volunteers were reliant on the Community Development Officers to develop the role for them, but it can be difficult for the Community Development Officers to

keep their volunteers engaged and occupied as there are not enough opportunities: *"we don't have stuff for 30, 40 volunteers at a time"*. Even when Community Development Officers did generate opportunities, they experienced some resistance from a minority of volunteers when trying to get them to engage with other communities because *"if that's not their community group they're not really that interested in coming along with us"*.

The volunteers who remained engaged with the project came from very varied backgrounds. This is beneficial in terms of diversity but can create challenges for the Community Development Officers who have to be able to cater for different needs and levels of knowledge. For example, some volunteers struggled to access training without easy access to a computer or due to language issues. Additionally, the training had too much information for some volunteers, while others found it too basic or unnecessary because of their previous experience and prior knowledge of dementia.

In order to address some of these challenges, the project has developed a short reference booklet called the 'Volunteers' Introduction to Dementia'. The Alzheimer's Society also has advice on its intranet regarding volunteer recruitment and management. It is suggested that the experiences from the Connecting Communities Project be incorporated where relevant for anyone working with volunteers, particularly those from BAME communities.

BAME community engagement

Groups and organisations

The Connecting Communities target of reaching 1,950 people from BAME communities was exceeded within the first six months of the project, and over 8,300 members of the public from BAME backgrounds have now been reached by the various awareness raising activities. A variety of communities has been engaged by the project, including: Afghan, African, Bangladeshi, Caribbean, Chinese, Greek, Indian, Somali, Tamil and Turkish, as well as further groups from Latin America, South Asia and the West Indies. So far, more emphasis has been put on the Black and Asian groups than, for example, some of the Eastern European groups. These latter groups have relatively young demographic profiles and their community groups can be difficult to identify.

It was appreciated that the project team has been successful at identifying *"small little community groups that exist out there […] whose members are interested in dementia, but they themselves haven't been part of the sort of wider […] dementia infrastructure"*. The Connecting Communities Project has therefore reached people who would not otherwise be part of the dementia 'system'. While it has not all been

straightforward, the project has been successful in engaging communities that can be considered 'hard to reach'.

Despite this success, the evaluation identified some concerns about the reach of the project. For example, it was suggested that people who participate in community groups and therefore attend the awareness sessions *"may not be representative of the population"*, and information may not always filter down to more isolated people in the wider community. While this is an understandable concern, it would be the same for any project targeting any form of group-based activity, and it is hoped that word of mouth will help to address this to some extent.

It has been noted that people are bringing friends and relatives to sessions after hearing a previous talk, and there has been a fundamental shift in terms of how links between the Community Development Officers and the community groups are being established. Rather than the Community Development Officers having to initiate all contact there are now many occasions where community groups are requesting awareness talks following recommendations from other groups. For example, as a result of doing one talk a Community Development Officer received four invitations to do further talks with different groups.

Although it has not been a core focus of the Connecting Communities Project, the Community Development Officers have been working with professionals and wider organisations, not just community groups. For example, the Community Development Officers have run dementia workshops for GPs and their staff teams which have included some of the issues faced by BAME communities. As can be seen from Figure 3, over 2,500 professionals have come into contact with the Connecting Communities Project with approximately 80% of those being within the eight boroughs targeted by the project.
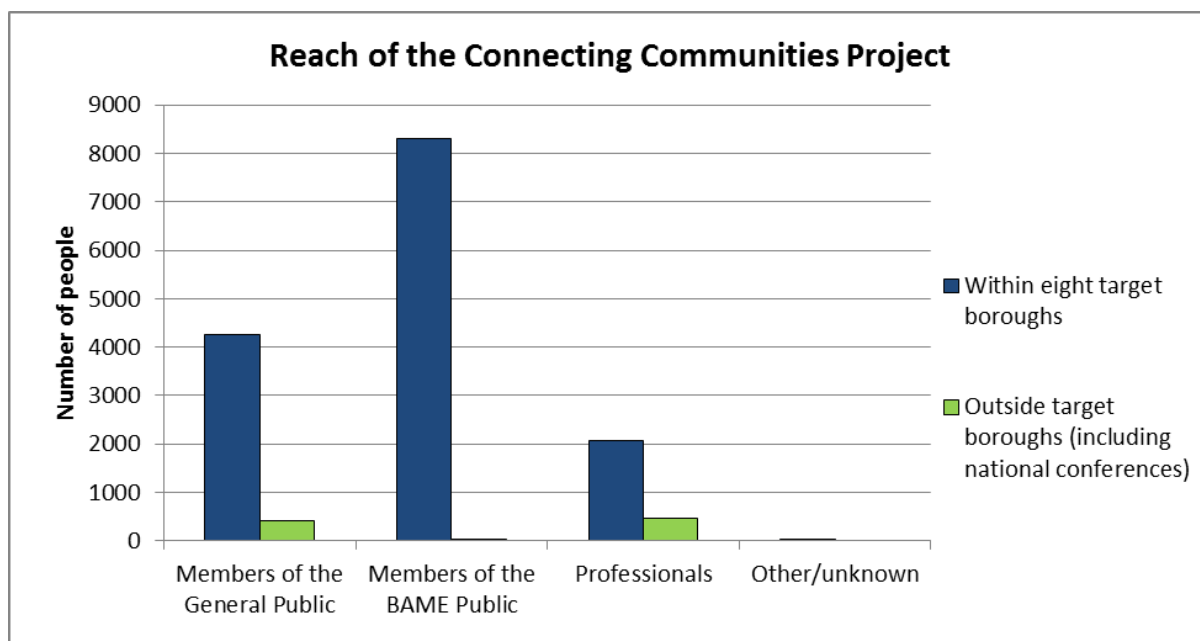
Figure 3: Reach of the Connecting Communities Project within and wider than the target boroughs

Addressing BAME needs

When asked in the survey how dementia awareness should be improved amongst BAME communities, the responses indicated that the Connecting Communities Project is approaching the challenge in ways that are appropriate and effective.

While it was considered useful to have information available in diverse formats such as in different languages or visually, how it is delivered can be more important. Providing the information in a range of locations can help as people may discover it by chance or when they do necessarily realise that they need it, rather than having to search for information and not knowing where to look. Sessions delivered in person were also considered to be important and were the most popular option chosen by BAME community groups across the surveys. The Connecting Communities Project approach of bringing the information to the groups in the form of face-to-face talks using slides with appropriate language and pictures is meeting the main requirements of the BAME communities.

In addition, survey responses suggested that linking dementia awareness to church services or multi-faith meetings could be beneficial, which is promising in terms of the work being done around dementia-friendly churches and the fact that some awareness sessions have already been delivered to religious groups.

The survey also explored how people from BAME communities access services, including dementia-specific services. Table 2 provides a summary of the responses,

and it can be seen that many of the barriers and facilitators are opposites. While many of these are beyond the control of the Connecting Communities Project, it is directly helping to address some of the barriers by raising awareness of services and reducing the stigma of dementia amongst BAME communities. It is also reassuring to note that many of the facilitators are features of the approach used by the Connecting Communities Project.

Table 2: Accessing services

Barriers	Facilitators
Not knowing about a service or what it offers	Publicity and a good reputation, word of mouth
Language issues such as information not being in an appropriate language	Resources in different languages, workers who speak different languages
Think service is not applicable to people from their BAME community	Recommendations from people within their own community
Cultural awareness and knowledge of staff	Workers who understand different cultures
Potential financial implications	Free services
Stigmatisation of dementia	
	Friendly staff and a friendly environment
	Easy to access, good transport links
	Time to develop trust and build relationships

Facilitators and barriers to engagement

Groundwork

At the start of the project the Community Development Officers spent time carrying out initial research to identify the main BAME groups and community organisations within their boroughs. This involved a combination of internet searches, information from local councils, BAME forums, Community Volunteer Services, and walking around the boroughs. While this was a useful exercise, it was commented that it would have been beneficial to spend more time getting to know the local communities and making contacts. This was considerably easier where information about community groups is well-organised and easy to access.

Some information, especially on the internet, can be old or out of date, or relate to groups that do not actually exist in reality. Consequently, the Community

Development Officers found that they could waste a lot of time chasing down potential contacts that eventually come to nothing.

In addition, there were difficulties making contact with some groups as they did not always respond to emails or telephone calls. In these cases it was often better to go and visit organisations in person as a physical presence is harder to ignore, and experiences showed that *"when you do get hold of them, and engaged, they're great, but they're just impossible to get hold of"*. Similar approaches were also required for organisations without an online presence, not just to make contact but to identify them in the first place.

This highlights the importance of *"going out and getting to know so many people from different communities"* in person rather than relying on modern technology. As one Community Development Officer said:

> *"we need to have information about what's going on in each borough because there are so many events [organised] by the community, we need to know what's going on so we can tap in"*.

It was considered beneficial to go to general community events to show an interest and get your face known. They are a chance to make people aware of the Connecting Communities Project and provide networking opportunities to start building relationships with individuals and groups.

Relationships and trust

The importance of developing relationships with community groups and building trust should not be underestimated. As one Community Development Officer said, *"if they don't trust you, it's not going to work"*. It is important to build time for this into the project timetable, even though the work may not have immediate results.

Keeping in touch following an awareness session can also be beneficial as the Community Development Officers have found that it makes it easier to do further sessions with community groups and they may also get invited to other events that they would not otherwise have known about. The strong relationships that the Community Development Officers have been able to develop during the project should ideally be maintained after the project has ended as they could help to facilitate further collaboration with the Alzheimer's Society in the future.

Word of mouth

Making the effort to build relationships and develop contacts can also have a longer-term benefit. It is important that information about the Connecting Communities Project is disseminated to groups to encourage wider engagement, but this is only

possible if the community groups can be identified. Consequently, word of mouth can often be the most powerful and effective way to spread information, and having a good contact can result in recommendations and introductions to other groups. For example, one Community Development Officer made a link with a local Councillor who was from a minority ethnic group, and they were able to help the Community Development Officer engage with relevant groups.

The importance of word of mouth should not be underestimated. One Community Development Officer commented that if you approach groups out of the blue they can be reluctant to host an awareness session, but if they have the chance to see what a session is like or if someone from another group recommends a session they are a lot more receptive.

Tailored approach

When trying to engage with different community groups it is necessary to understand specific cultural issues. For example, one Community Development Officer was trying to engage with a group that believes *"if you speak about something you increase the likelihood of it happening"*. This can create challenges and affect how a group is approached. As one Community Development Officer said, *"how do you raise awareness of something when you're sort of restricted about talking about it?"*

Understanding individual groups and tailoring your approach accordingly is important because what works for one group will not necessarily work for another: *"you can't engage with any group exactly the same way as you do with another group"*. Even when you think groups might be similar they can be very different. This was reflected in the fact that communities the Community Development Officers struggled to engage in some boroughs were not a problem in other boroughs. The Community Development Officers therefore require an understanding of the cultural diversity within an area. This might include considering factors such as holidays, festivities and religious activities, both when trying to contact a community group and when agreeing a time for session.

Sharing information about communities can be helpful to the Community Development Officers when deciding how to approach some community groups. The Community Development Officer who started part-way through the project commented that they were able to use information gained from the other Community Development Officers' previous experiences in terms of knowing what is or is not acceptable when meeting groups, such as covering your hair, wearing modest attire, and whether you can talk to a group of the opposite sex. Knowledge of this sort gained during this project is very valuable for future use.

Level of interest

The ability to engage with a community group can often depend on the level of interest within the group. It was noted that the current media focus on dementia has been helpful and may have increased the willingness of some groups to have awareness sessions. The launch of the All-Party Parliamentary Group report[11] on dementia in 2013 was particularly useful for the project team as it provided evidence of why the Connecting Communities Project was needed and encouraged groups to engage.

However, some community groups were not interested in sessions or engaging with the project without a financial benefit for them, and others were simply not interested or will not engage *"no matter how much you try"*.

Awareness activities

Range of activities

The main activities undertaken by the Community Development Officers were awareness raising sessions. Group sizes ranged from approximately ten people to more than 70, and sessions lasted anywhere from ten minutes to two hours. The Community Development Officers generally preferred to deliver shorter sessions because they felt this maximised engagement and interest from the group. The sessions were generally felt to be a success, and when some aspects did not quite work as intended the Community Development Officers were able to learn from their experiences and adapt future sessions as a result.

The variability between sessions reinforces the skills required by the Community Development Officers regarding the need to be confident, flexible and adaptable. This was also seen when awareness sessions were part of wider meetings or events, when timings are more likely to be affected. For example, if previous speakers or parts of the meeting overrun, the time left for the dementia awareness session may be less than expected, forcing the Community Development Officer to revise their presentation as they go along. Conversely, although the allocated time may not change, the event schedule may alter. One extreme example of this was when a Community Development Officer began their 20-minute session three hours later than anticipated. In total, the session required the Community Development Officer to be at an event for five hours, which is not particularly time-effective for a short presentation and not the sort of time commitment that a volunteer could be expected to make.

---

[11] House of Commons All-Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities*

In addition to the awareness raising sessions, the Community Development Officers ran roadshows, workshops, information stalls and events to bring together different organisations within the community around topics such as health and well-being, healthy eating, and music and dementia. The project also provided the opportunity to run Dementia Friends sessions for some groups as a follow-on engagement activity, and while this is not strictly within the scope of the Connecting Communities Project it has helped to develop and sustain relationships within the local communities.

The Connecting Communities Project has also influenced the way other Dementia Friends sessions are run, as some Dementia Friends staff have attended sessions run by the Community Development Officers and adapted their sessions for BAME communities. New resources and materials rely less on written English to make them more appropriate for different groups, and the Connecting Communities Project team is helping to pilot these resources. The reach of the Dementia Friends initiative is also increasing as BAME communities are being encouraged to become Dementia Friends, which is an unexpected benefit from the project.

Planning and running awareness sessions
Practicalities

As recognised in the interim annual report, the Community Development Officers experienced various practical and technical issues when delivering their awareness raising sessions. For example, community groups do not necessarily have appropriate equipment to support a PowerPoint presentation and the Community Development Officers were not always able to take their own with them, or a venue may not be appropriate in terms of size or acoustics. The need for a translator or interpreter – as covered later in this section – can also be an issue when the Community Development Officer has been informed that it is not necessary.

These issues have persisted and the Community Development Officers are sufficiently experienced to deal with whatever situation the face. They also try to check equipment availability prior to a session and often take printed copies of slides as a contingency. As most groups appear to have a television and DVD player it has been suggested that having a copy of the presentation on DVD may be an alternative option worth considering.

Sessions tended to run more smoothly when the local group organiser was fully engaged and on hand, and when the group was aware that the session had been scheduled, which has not always been the case in practice. This greater engagement is often linked to groups where the Community Development Officers have had more contact, reiterating the importance of having the time to develop relationships with the community groups.

Presentation slides

The presentation used by the Community Development Officers during their awareness sessions has developed and grown throughout the project, with the style and order being adapted in accordance with recommendations from the interim annual report. These recommendations were based on the initial session observations carried out by the evaluation team, and subsequent observations indicate that the revisions have been successful.

The Connecting Communities team has developed an overarching presentation that contains all possible slides and encompasses a core set of slides with the key messages that should be included in all sessions. The Community Development Officers are then able to choose the slides that are relevant and appropriate to the particular session and group they are planning, tailoring them to the specific needs or preferences of that community group. For example some groups like pictures and visual representations, while diet and risk factors for dementia are often popular topics.

The slides are also flexible enough for the Community Development Officers to adapt in response to questions or points that may arise during the actual presentation.

During the development of the presentation slides it was recognised that some examples and analogies used did not always work as intended. For example:

- The slide comparing pictures of a healthy brain and a diseased brain is sometimes misunderstood as the healthy brain can be seen as being swollen rather than the diseased brain having shrunk. Simply labelling the two images may help to reduce this confusion;

- The bookcase model has not always been successful as it can be difficult to explain clearly and some groups may not necessarily understand the underlying concepts for cultural reasons. It should be noted that during the follow-up session observations, the evaluation team saw a clear, simplified version of the bookcase model that was very effective.

While the presentation slides have improved with time and experience, two challenges remain and have been seen during the session observations:

- **Clarity and visibility** – During one session the Community Development Officer was presenting in English but the slides had been translated in order to ensure that the information was accessible to everyone in the group. While this was a good idea, the Community Development Officer needed to see the notes pages associated with each slide to know which slide was which. Ideally, the notes should have been printed off to ensure that the slides could be shown full screen to maximise their clarity and visibility to the group. In practice, the notes were shown on the screen which reduced the

size of the slides and made the presentation busier and more confusing to read;

- **Timings** – A common problem with presentations in any context is to include too many slides. This can result in presentations being rushed or slides being missed as the presenter runs out of time, which can affect the impact of the presentation. The Community Development Officers therefore need to realistic about what they can cover within their allotted time. It may be preferable to have fewer slides and encourage more conversation and interaction.

Interaction

It was quickly recognised by the Community Development Officers that awareness sessions need to be interesting and engaging rather than just 'a talk'. As one Community Development Officer commented, *"you can't just give a presentation because you will lose them and they're not interested"*. The Community Development Officers have included more activities in their sessions than previously, making them more interactive. Incorporating activities and encouraging interaction work well and can help to get messages across in different ways that are less reliant on language skills. Additionally, visual activities can help people to see things from the perspective of a person with dementia.

One of the most popular activities used by the Community Development Officers is the cup of tea exercise, which has been adapted from the exercise used in Dementia Friends sessions and generally works well for most groups. This exercise gets groups thinking about the various steps involved in making a cup of tea to help them realise that 'simple' activities we take for granted can actually be quite complicated for a person with dementia. The exercise is easy to facilitate as it requires minimal resources, and can be used with groups of all sizes.

Another approach that works well is to use simple techniques such as asking the group questions. For example, rather than just presenting facts and statistics to a group, the Community Development Officer can ask them for their ideas and opinions, and see if other group members agree or think numbers should be higher or lower.

Interaction can be better when the groups are smaller as it can feel less formal and a more comfortable environment for asking questions, although the group dynamics can often have an impact on engagement. The Community Development Officers therefore have to respond to each group and adapt their presentation style accordingly, again highlighting some of the skills required to successfully undertake their role.

Interpreters and translation

The Community Development Officers have all been involved in delivering awareness sessions where English is not the best language to use with a group. When this happens and an interpreter is required, Community Development Officers have to plan their presentations differently in order to allow extra time for the translated version. While this may seem obvious, as one Community Development Officer pointed out, *"it makes sense when you think about it, but unless you've actually done it before you don't know until you get there"*.

A useful resource has been developed by the Connecting Communities team based on their experiences, providing guidance regarding how to work effectively with interpreters. This resource includes practical advice covering all stages of the process, and will be beneficial to workers both within and beyond the Connecting Communities Project.

As indicated previously, the Community Development Officers do not always know in advance that they will need an interpreter, and sometimes only discover this when they arrive and meet the group. In these cases, the group leader or another member is often able to help out, but the Community Development Officer will need to be aware of some of the difficulties that this presents:

- **Time pressures** – If the Community Development Officer has not planned in the additional time required for interpretation, there is likely to be too much information to cover within the allotted time, requiring the Community Development Officer to adapt their intended presentation;

- **Language skills** – Some group members may not have sufficient language skills to be an effective interpreter. For example if they know English better than the required language they might not have a deep enough understanding of that language to get some of the details through to the group effectively;

- **Concept of dementia** – If the group member does not know about dementia and the Community Development Officer has not been able to discuss it with them beforehand – as they would do with a planned interpreter – they may have difficulties explaining some of the dementia-related concepts. This can be even more difficult if their language has no appropriate or acceptable word for dementia;

- **Misunderstandings** – Some group members may give incorrect information if they have their own misconceptions of dementia or mistranslate what the Community Development Officer has presented. They may also try to summarise what has been said rather than providing a full translation, which can again result in misinformation.

Impact of the Connecting Communities Project

Despite having to overcome various challenges along the way, the Connecting Communities Project has been highly successful. The key to this success has been the way in which the Community Development Officers have been given the flexibility to tailor their work to meet the needs of the local communities, which has ensured that the project has had an impact within and beyond those diverse communities.

While it had been hoped to use data regarding dementia diagnosis rates and borough-specific information on services to show the impact of the Connecting Communities Project, inconsistent and incomplete data recording by local organisations and services has made this unachievable. In addition, it is important to note that many other projects and initiatives have focused on dementia during the same period. This would make it difficult to attribute any changes in levels of awareness and service use to the Connecting Communities Project. The evaluation has therefore relied on information it has gathered independently from individuals and organisations directly related to the project to assess the specific impact of the work carried out by the project team.

Raising awareness

BAME community organisations

As mentioned previously, the initial project target of raising the dementia awareness of 1,950 people from BAME groups has been significantly exceeded with over 8,300 people – and counting – having been reached by the project. Through the awareness raising sessions it has been seen that:

- Community Development Officers have been able to address misconceptions regarding dementia that exist within BAME communities;

- People are understanding the potential impact that their lifestyle and diet may have in terms of being risk factors for dementia;

- People are appreciating the importance of seeking professional help when symptoms first appear rather than waiting until they have reached crisis point;

- Some people already had concerns about their memory but were unsure what to do about it or where they could seek help;

- People are more aware of the dementia services available within their local areas. 33% of dementia services responding to the final evaluation survey (n=6) indicated that they have seen an increase in the number of people from a BAME background accessing their services during the lifetime of the project. This increase was general and did not apply to any BAME community in particular;

- Carers are developing a better understanding of what their loved ones are experiencing and why they may behave in certain ways.

As can be seen from Figure 4 the self-rated dementia awareness of the BAME community groups who received sessions from the Community Development Officers improved during the course of the project. At the start of the evaluation only 40% of groups (n=10) rated their own dementia awareness as 'good' or 'very good', but this had risen to 60% by the time the follow-up survey was conducted. In the final survey, 69% of BAME community groups (n=13) reported that their dementia awareness had improved following their sessions with the Community Development Officers. As summed up by one survey respondent, *"what was certain is that after tonight's presentation, people would leave better informed than when they arrived"*.
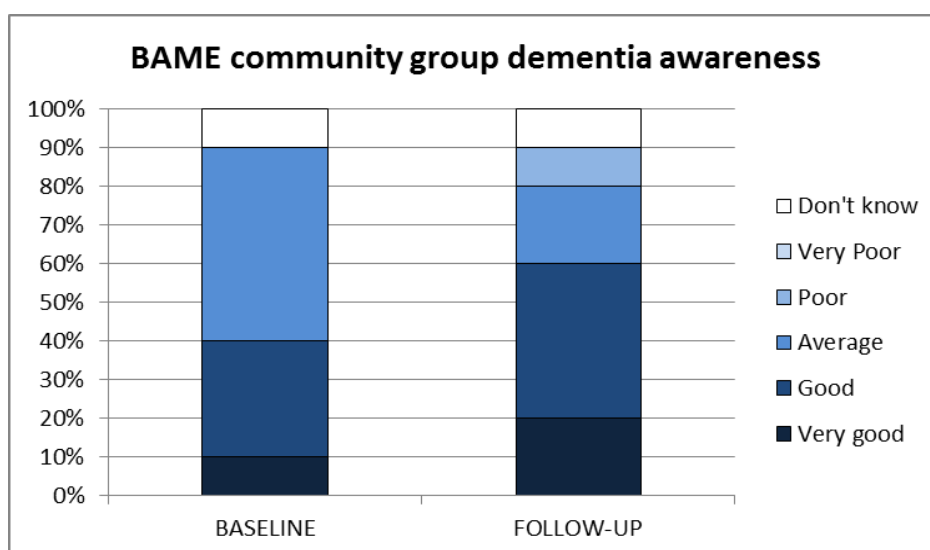
Figure 4: Self-rated dementia awareness of BAME community groups

When compared with Figure 5, the results in Figure 4 also indicate that BAME community groups felt that after receiving the awareness sessions their dementia awareness was greater than that within the general community. Indeed, by the follow-up survey the percentage of BAME community groups with 'good' or 'very good' dementia awareness (60%) was double that of the general community (30%).

General community dementia awareness
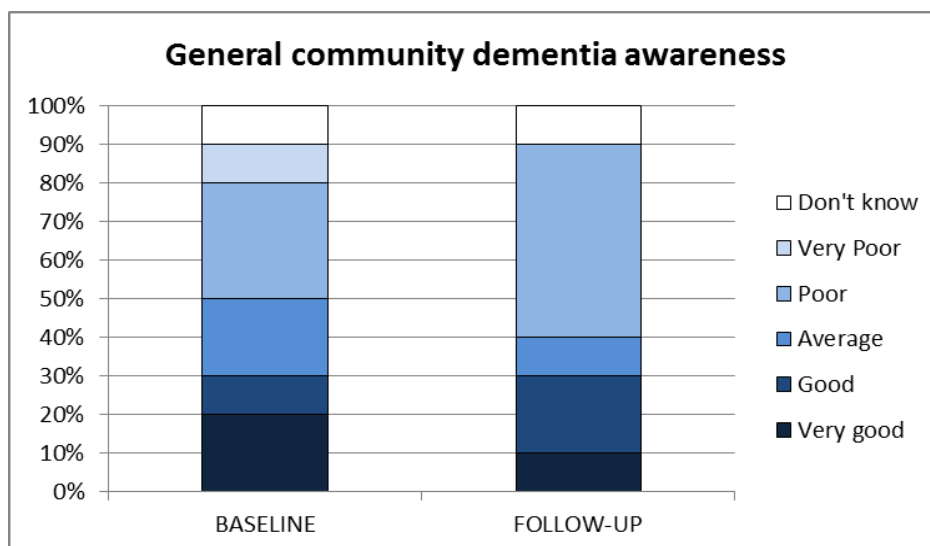
Figure 5: General community dementia awareness as rated by BAME community groups

Session feedback

> *"The organisers and the Chair should be applauded for providing the opportunity to encourage people to become more aware of the importance of maintaining good mental and physical health and wellbeing"*

> *"I thoroughly enjoyed the session by the Alzheimer's Society. It gave us a greater understanding of dementia and what form dementia can take."*

As suggested by the above comments, the sessions were well-received by community groups and the observed sessions all had positive feedback. People were engaged with the sessions and found them *"interesting"*, *"very useful"*, *"worthwhile"* and a source of *"good information"*. Following one session an ex-nurse commented that it had been *"brilliant"*, and it was also reported that the dementia awareness sessions were more interesting than other speakers some groups have hosted. Groups commented that there was nothing they disliked about the sessions, but wished there could be more sessions overall.

The fact that the Community Development Officers are often invited back for longer sessions or follow-up sessions, or recommended to other groups also speaks highly of how they have been received. Indeed, survey responses showed that 100% of the responding BAME community groups would encourage other groups to have similar awareness sessions. One respondent reported a need to *"do more of these events"* and felt that *"more organisations should be encouraged to make use of the awareness sessions"*.

Additional feedback gained via the final survey included the following comments:

"All their questions were answered by staff in 4 Asian Languages"

"The session was well organised and facilitated"

"It was very informative & we learned a lot"

"I think the connecting communities project has proven to be very successful with our organisations, we have good links with the officers of this project and would hope that the service continues in the future"

Wider services and organisations

In addition to the sessions specifically targeting BAME communities, the Connecting Communities Project had a much wider impact in terms of raising awareness of dementia and BAME issues through its other activities including:

- GP workshops, together with Dementia Friends sessions where the Community Development Officers have incorporated BAME information;
- Information stalls and events in public areas including libraries and market places;
- Information stalls in hospitals, which can benefit professionals as well as the general public;
- Community Development Officers and volunteers engaging with local Alzheimer's Society staff and services such as dementia cafes.

Consequently, over 2,500 professionals and a further 4,600+ members of the general public have been reached by the Connecting Communities Project through these additional activities.

While survey responses also showed that dementia services were already 'mostly' or 'totally' accessible to people from a BAME background (Figure 6), there was further improvement during the course of the Connecting Communities Project. Indeed, services reported a range of measures they had implemented to become more accessible including:

- Simplifying their information to make it jargon free;
- Recruiting staff with different language skills;
- Referring people to organisations that can provide BAME-specific assistance;
- Setting up outreach stations within the community to make it easier for people to see a Support Worker.

These responses indicate that there is an increasing awareness of the issues faced by people from BAME backgrounds and of the importance of addressing these issues.

Accessibility of dementia services

	Not at all
	To some extent
	Mostly
	Totally

BASELINE FINAL
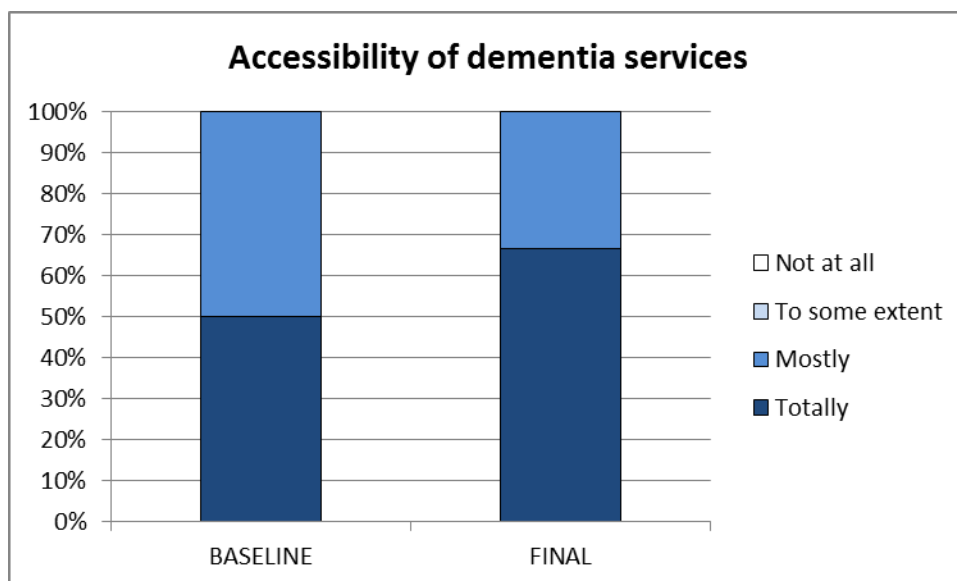
Figure 6: Accessibility of dementia awareness for people from BAME community groups

Project reach

As indicated previously, the reach of the Connecting Communities Project has exceeded the people who have attended the dementia awareness sessions. In total, over 15,500 people have come into direct contact with the Connecting Communities Project through their sessions and other events and activities. However, the true reach of the project extends even further. At the most basic level, people have shared what they learnt during the awareness sessions with their family and friends and encouraged them to attend other sessions that they heard about.

Additionally, following sessions groups have recommended the project to other groups, which has resulted in requests from community groups both within the target boroughs and further afield. Contacts made through the project have resulted in several spin-off initiatives such as the resource pack to make churches more dementia-friendly, which will be used beyond the target boroughs.

Anecdotal evidence indicates that contacts made with local authorities, involvement with local Dementia Action Alliances, and feedback to the project Steering Group have made local Commissioners more aware of BAME communities and the related issues around dementia. One example of this is the creation of a dementia café in Croydon where the Alzheimer's Society *"used its knowledge from its 'Connecting*

Communities' project"[12] after Croydon Council realised that *"there was a need for a culturally specific form of support for people living with dementia in Croydon"*[12].

The Connecting Communities Project has also received national – and potentially international – coverage including:

- An article in The Journal of Dementia Care[13], 2015;
- Inclusion as a case study in the latest version of the Prime Minister's Challenge on Dementia[14], 2015;
- Inclusion as a case study in the book 'Dementia, Culture and Ethnicity'[15], 2015;
- A presentation at the UK Dementia Congress in Brighton, 2014;
- Inclusion as a case study in the All-Party Parliamentary Group on Dementia report[16], 2013;
- Inclusion as an example resource in a Better Health briefing paper[17], 2013.

As noted by one of the projects' stakeholders, it should be applauded that by working with local communities at grass roots level the Connecting Communities Project has enabled BAME issues to be raised at a national level.

Legacy

While the Connecting Communities team and Steering Group are pleased with the success of the project, the challenges around its legacy and sustainability have been recognised. Although fewer volunteers were recruited than initially planned, there remains the potential for those who participated in this pilot to help maintain awareness and interest in dementia within their boroughs.

Survey responses indicate that 46% of BAME community groups who received a dementia awareness session were involved in further activities around dementia. These include:

- Activities to further improve group knowledge such as Dementia Friends sessions and question and answer sessions in different languages;

---

[12] Case Study: The Jasmine Café – Health Innovation Network South London http://www.hin-southlondon.org/system/resources/resources/000/000/086/original/Case_Study_The_Jasmine_Cafe.pdf?1426083568 (accessed 15/07/2015)

[13] Leatherland, S. and Anthony, A. (2015) Connecting Communities: sharing the learning. *The Journal of Dementia Care*, 23, 4, 14-15

[14] Department of Health (2015) *Prime Minister's challenge on dementia 2020.*

[15] Botsford, J. and Harrison-Dening, K. (2015) *Dementia, Culture and Ethnicity: Issues for all*. Jessica Kingsley.

[16] House of Commons All-Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities.*

[17] Truswell, D. (2013) *Better Health Briefing 30: Black, Asian and Minority Ethnic Communities and Dementia – where are we now?* A Race Equality Foundation Briefing Paper.

- Awareness events for the wider community;

- Individuals attending dementia meetings to maintain their own knowledge;

- Reminiscence groups and singing and exercise sessions within the community group.

Learning about dementia has also encouraged one community group to consider mental health more generally and they have subsequently hosted a speaker on this subject.

Resource development

One of the main legacies from the Connecting Communities Project is the set of resources that have been developed, which will be useful on a wide range of work involving volunteers and/or BAME communities. The resources include:

- The 'Volunteers' Introduction to Dementia' leaflet to help volunteers improve their knowledge of dementia;

- The 'What is dementia?' leaflet which will be available in English, Chinese, Punjabi, Urdu, Hindi, Polish, French, Bengali, Guajarati, Turkish, Tamil and Somali. This can be used to support dementia awareness raising activities within different community groups;

- The guidance on working with interpreters and translations.

It is also understood that the team are in the process of using their experiences and knowledge to produce a toolkit of guidance and information regarding how to understand ethnicity within local areas and how to work with different BAME groups. It is anticipated that this will be a valuable resource and lasting legacy from the project.

Wider activities

The Connecting Communities Project team has been involved with several 'added value' activities that will contribute towards the longer-term impact of the work, particularly in terms of raising dementia awareness. Two key examples are:

1. The resource pack to help churches become more dementia-friendly, which is also being developed for mosques;

2. A play developed and performed by a community group that a Community Development Officer worked with, which is being used to raise awareness of dementia within and beyond London and can be performed in both English and Hindi.

A summary of some of the activities that have taken place during the Connecting Communities pilot showing its impact, reach and legacy is shown in Figure 7.

Wider work and involvement

Providing BAME information to local Dementia Action Alliances

Receiving BAME information sessions from Local Councils

Volunteers recruited through the project supporting local services

Connecting Communities

Core Work

Dementia awareness sessions

Information stalls

Roadshows

Community events

GP workshops

Resource development

LEGACY: Volunteers, resources and toolkit

Development of the resource pack for dementia-friendly churches and mosques

Development of the dementia play in English and Hindi

Running Dementia Friends sessions for professionals

Local Commissioners building on the Connecting Communities work to look beyond dementia at BAME communities more widely

Working with the Dementia Friends initiative to make their resources appropriate for BAME groups

Running Dementia Friends sessions for community groups
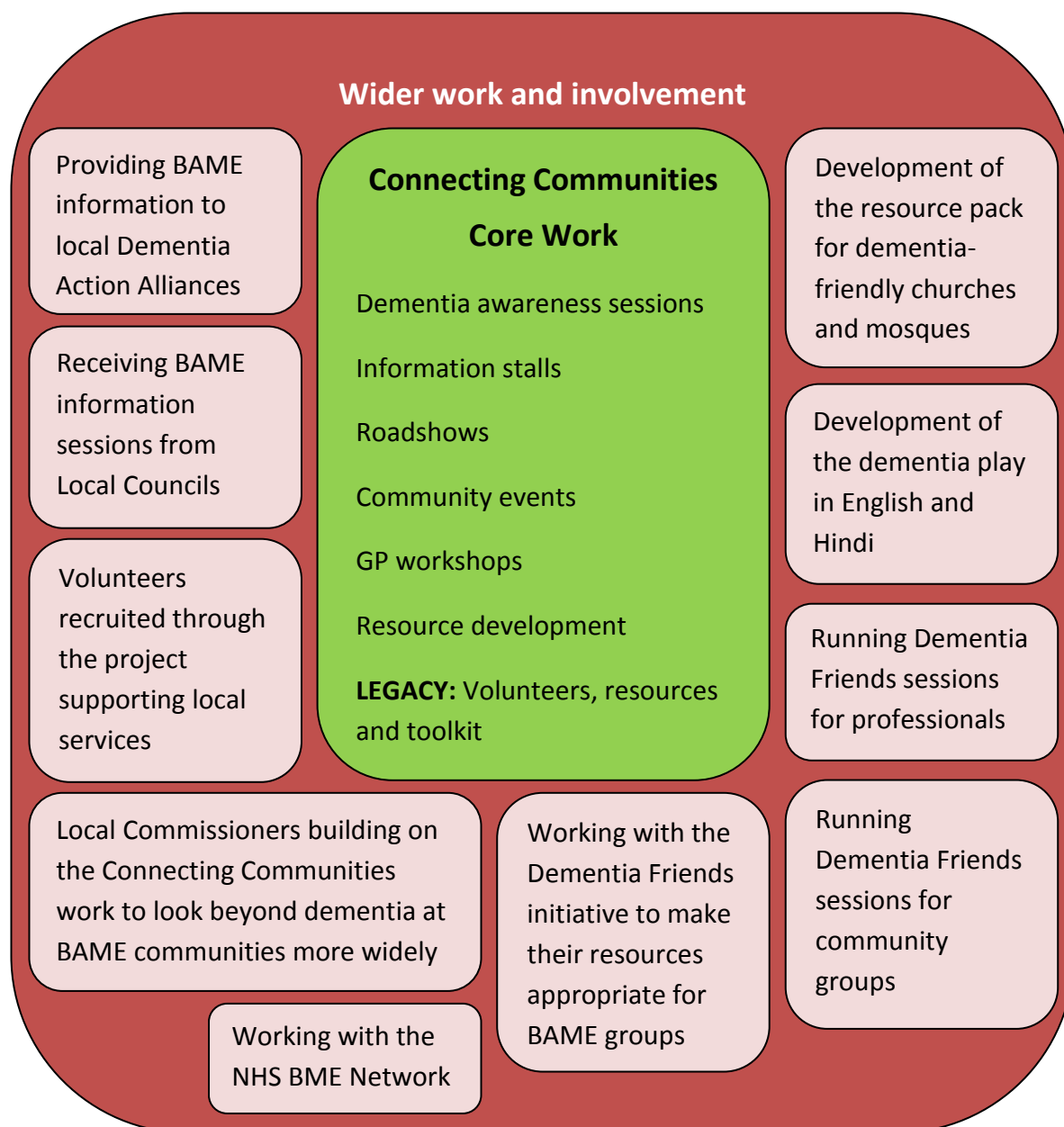
Working with the NHS BME Network

Figure 7: Appreciating the impact, reach and legacy of the Connecting Communities Project

Discussion

This section draws together the evaluation findings as reported above and discusses them in terms of four key outcomes of the Connecting Communities Project.

Outcome 1: Engagement with BAME communities and community-specific dementia health care providers

In addition to the survey responses indicating that 33% of dementia services (n=6) saw an increase in the number of people from BAME communities engaging with them, the following two examples suggest a similar impact on Alzheimer's Society services.

1. The Alzheimer's Society Services Manager for Hounslow reported that for one of their new services 50% of referrals were from Asian backgrounds and 50% from White British backgrounds, which is more reflective of the need within the local community. In addition, their Singing for the Brain service has a very diverse attendance with only one carer being White British. Overall, they felt that their client base for some services has changed within the past year, and was likely to coincide with the work being done by the Community Development Officer in that borough;

2. In Merton, the Alzheimer's Society Services Manager for the borough reported that in the first three months of 2015 14% of people attending dementia cafes in the area were from BAME communities. This is an increase from 8% for the same period in 2014. While these figures are still relatively low, it was considered that the work being done with local BAME organisations to raise awareness was having an impact and the people contacting the Alzheimer's Society were from more varied backgrounds than seen previously.

Furthermore, feedback from the Community Development Officers has indicated that during their dementia awareness sessions they have had people with dementia in the audience and been able to refer them to appropriate services that they did not know existed. Indeed, when talking to some participants following the session observations it was noted that they had been worried about their memory but now felt more confident about knowing what their options were and the importance of seeking help.

Despite the progress that has been made, it was recognised that there remain barriers to people from BAME engaging with local services. Although the Connecting Communities Project is unable to influence some of these, it is directly tackling barriers around awareness of services and the stigma of dementia within some BAME communities.

Outcome 2: Dialogue between BAME communities and the Alzheimer's Society and wider stakeholders

Through the efforts of the Connecting Communities team an increasing network of relationships and trust has been established between the Alzheimer's Society, local BAME communities and a variety of professional organisations. Survey responses indicated that some BAME community groups from a variety of different faiths and backgrounds felt they had good relationships with the Community Development Officers and were also aware of their connection with the Alzheimer's Society.

Within the BAME communities, initial contacts resulted in word of mouth recommendations and making connections with community groups that the Community Development Officers may otherwise not have been able to engage with. As the project developed, community groups began to approach the project team requesting dementia awareness sessions, indicating their interest and the importance of the work being done. Requests also came from groups outside of the eight target boroughs and Community Development Officers have been asked why the Connecting Communities Project is not available more widely.

The relationships that were established have also been beneficial in terms of being able to engage community groups to assist with the development of the new translated resources. As well as ensuring that these resources are appropriate for their target audience, this process has helped to reinforce contacts and give the community groups a sense of ownership as a result of their involvement.

In addition to dementia awareness sessions, the Community Development Officers receive invitations to wider community events, and have been involved in other initiatives that would not directly be considered a core part of the Connecting Communities Project. These include the dementia awareness play, the dementia-friendly churches resource pack, working with local councils and having a presence in local Dementia Action Alliance groups. Apart from strengthening connections and helping to raise dementia awareness more widely, this work provides a platform for getting BAME issues onto wider agendas and bridge the gap between communities and stakeholders.

Outcome 3: Dementia awareness and knowledge of dementia care services in BAME communities

During the Connecting Communities Project over 8,300 people from a wide variety of BAME community groups have benefitted from the 540+ dementia awareness sessions, talks and events that have taken place. These activities not only helped to increase the levels of dementia awareness within these communities, especially when compared to the awareness of the wider community, but also provided

valuable information regarding dementia support services available to them as potential users or as carers. Service information has been a particular focus of sessions that the Community Development Officers have delivered in conjunction with Dementia Advisers or Dementia Support Workers from local Alzheimer's Society teams.

All BAME community groups responding to the evaluation surveys appreciated the importance of their own services being dementia-friendly and said that they would encourage other organisations to receive dementia awareness sessions. Observations by the evaluation team have confirmed the success of the sessions and demonstrated that participants understood the main messages being presented. Increased knowledge and interest in dementia has resulted in information being shared more widely with family and friends, helping to increase awareness amongst people who the Community Development Officers may otherwise be unable to reach.

While having translated leaflets and resources might have assisted the dissemination of dementia information, especially when English is a second language, their unavailability does not appear to have had a negative impact on the success of the project. Indeed, the development of accurate and appropriate resources in conjunction with volunteers and community groups will leave a lasting legacy.

Outcome 4: Understanding amongst professionals of dementia-specific issues faced by BAME groups

Although the original focus of the Community Development Officers was on engaging with BAME communities rather than professionals, the project has in fact made good progress in this area. The team increased their efforts after the interim annual report reiterated its importance, and across the project as a whole the team has succeeded in reaching more than 2,500 professionals.

Health care professionals

The Community Development Officers have worked with GPs and managed to incorporate BAME aspects into Dementia Friends sessions that they have delivered as a crossover between the Connecting Communities Project and the Dementia Friends initiative. The information stalls that have been run within hospitals are also likely to have had an impact on professional understanding of dementia.

As seen from the survey responses, dementia service providers feel that they have become more accessible to people from BAME communities, with 67% of services (n=6) now feeling that they are 'totally' accessible compared to 50% (n=12) at the start of the project. Some services also took measures to address potential barriers associated with communication and language skills, service location and cultural

awareness. These indicate that there is an increasing awareness of the issues faced by people from BAME backgrounds and of the importance of trying to address these issues.

The Alzheimer's Society

In addition to working directly with health care professionals, the Connecting Communities Project has had an impact within the Alzheimer's Society itself. Working within local Alzheimer's Society offices in some boroughs has enabled the Community Development Officers to raise awareness of the Connecting Communities Project amongst the staff teams, involve staff in sessions with BAME community groups, and include them in sessions providing information about specific BAME communities.

Additionally, some volunteers originally recruited through the Connecting Communities Project have become involved with wider Alzheimer's Society services such as dementia cafes, helping to make them more diverse services and raising awareness of BAME issues.

Consequently, the Alzheimer's Society now has a greater recognition of the importance of focusing on BAME communities and the need to provide culturally-appropriate services.

Commissioners

As a result of the contacts and relationships developed during the Connecting Communities Project, commissioners in many of the target boroughs have made substantial efforts to engage with the work being done. Additionally, the Steering Group has seen an impact amongst the local commissioners across London more generally. There is felt to be a greater appreciation of the challenges around diagnosis within BAME community groups and the lack of appropriate support.

Consequently, there has been recognition of the need to deliver dementia awareness sessions flexibly to take account of the needs of people from different minority communities, which has been one of the key strengths of the approach adopted within the Connecting Communities Project.

Wider professional awareness

Publications referencing the Connecting Communities Project and journal articles and presentations describing the work provide another avenue for getting BAME issues onto the national agenda and drawing them to the attention of a wider range of professionals.

Conclusions

This report highlights the significant amount of work that has been undertaken by the relatively small team working on the pilot Connecting Communities Project. The team has overcome a variety of challenges that emerged over three years to achieve their overall aim of engaging volunteers to design and deliver activities raising dementia awareness across eight London boroughs. As with most pilot projects, not all aspects progressed as planned, but the project incorporated sufficient flexibility to allow the structures and processes to be adapted in order to achieve the desired impact.

Although fewer volunteers were engaged in the project than intended – two thirds of the revised target of 150 – and the number actively involved in delivering dementia awareness sessions has been low but steadily increasing, their input has been invaluable in shaping the design and delivery of activities. This included helping to develop appropriate resources that not only support dementia awareness activities within the Connecting Communities Project but will also be a lasting legacy of the project that can be implemented more widely within the Alzheimer's Society. Additionally, the importance of volunteer involvement in terms of producing newsletters and running information stands should not be underestimated; these forms of volunteer engagement can also be considered as delivering dementia awareness activities to the wider public.

The achievements of the Connecting Communities Project are all the more impressive when it is appreciated that the team had to take a step backwards in order to move forwards in terms of redeveloping the translated resources previously available within the Alzheimer's Society. While the extra work created by this shifted the focus of the project away from volunteer recruitment to some extent, it was justified by the importance of the resources in the longer-term.

The Community Development Officers took on much of the delivery work that was originally intended for the volunteers, while also needing to establish a balance between this outreach work and volunteer management. Achieving this was helped by the lower numbers of volunteers involved in the project, which highlighted the fact that managing the anticipated volunteers would not have been feasible with the revised project structure.

The main activity undertaken within the project was the delivery of dementia awareness sessions to BAME community groups, with the ground work for this requiring significant time and effort. While engagement has not always been straight forward, the perseverance and commitment of the Community Development

Officers and Project Manager resulted in over 8,300 people from BAME communities participating in awareness raising sessions, significantly exceeding the original target of 1,950. It is important to recognise the wider reach of the project through people sharing information from the sessions, other Connecting Communities activities, and the involvement of the team in related work that emerged from the project. Impressively, more than 15,500 people have been reached by the Connecting Communities Project as a whole.

The dementia awareness sessions were well-received by the BAME community groups involved, and have been adapted, developed and refined across the lifetime of the project. The use of an overarching presentation from which appropriate slides can be selected supported an adaptable approach that enabled the Community Development Officers to tailor their dementia awareness sessions to meet the specific needs and preferences of different communities and groups. The toolkit which is currently in development will be based on the knowledge and experiences of the Connecting Communities team and provide general guidance on working with BAME communities. When combined these two elements will form an overarching template, as favoured by Commissioners, which is flexible enough to recognise that every community group is different.

The challenge for the Connecting Communities Project now is legacy. The resources developed during the project and the subsequent toolkit are a significant step towards ensuring the legacy of the project. Additionally, the learning from this pilot project has created a strong platform from which to take this work forwards. It has presented a clearer idea of what works and what does not work when engaging BAME communities in terms of the activities delivered, the underlying management and support structure, and the skills required by the Community Development Officers.

Recommendations from the Connecting Communities Project evaluation

The recommendations presented in this section are designed to be useful in two respects: firstly to help develop the existing project and secondly to help establish or expand the work into new areas.

Finalising the work from the pilot project

The pilot Connecting Communities Project has overcome many challenges, and the learning from the experiences of the project team is valuable. Much of the information sharing between the Community Development Officers has been informal and verbal. It is therefore important that all relevant information is captured and disseminated appropriately. This might be best achieved through the completion of the following key project outcomes and resources:

- The dementia introduction booklet for volunteers will be a valuable resource for all new volunteers and could also be made available more widely within the Alzheimer's Society;

- The information held on the Alzheimer's Society intranet regarding working with volunteers needs to reflect the experiences of the project team and capture the learning from the Connecting Communities project;

- The 'What is Dementia?' translated leaflet will provide a key resource for all dementia awareness sessions and activities in the appropriate language(s). It could also be made available more widely within the Alzheimer's Society;

- The guidance regarding translation and interpreting needs to be finalised, ensuring that it captures the learning from the project and practical advice based on the team's experiences;

- The overall toolkit is grounded in the project team's experiences of what works well and what would have been useful for them to know before the project started. It could include useful information about different BAME communities, the demography of the local area, advice on identifying and engaging community groups, and advice on dementia awareness activities with different target audiences.

Recommendations for the Alzheimer's Society

Based on our evaluation of the Connecting Communities Project and the challenges encountered during the pilot phase, the following recommendations are intended to support future work by the Alzheimer's Society:

- **Project structure** – The key elements required to support a large, complex project such as Connecting Communities are:

- o A central office base for the project team;

- o A Project Manager, preferably full-time;

- o Administrative support;

- o Regular supervision and peer support groups for Project Officers;

- o Appropriate equipment to support the delivery of awareness sessions in a variety of locations;

- o A database to record information about all relevant activities undertaken during the project.

- **Embedding new projects within local Alzheimer's Society teams** – The effectiveness of new initiatives such as the Connecting Communities Project can be maximised by ensuring they are integrated with local Alzheimer's Society teams. This requires an understanding of the project aims and structure. Where possible team members can work with project officers by, for example, delivering joint presentations. The local teams will should be aware that a project has the potential to increase demand for services;

- **Project approach** – It is important to consider whether the focus of a project should be on communities or geographical locations. Assuming that the project is expanded across London, this may not be an issue as all areas would be covered by a Community Development Officer;

- **The Community Development Officer role** – The role should be clearly defined with a common understanding of expectations and responsibilities. This will help the Community Development Officers to balance the different elements of their work. In addition to working with volunteers and raising dementia awareness amongst BAME communities, the role needs to encompass raising awareness of BAME issues amongst professionals and dementia services. This will ensure that when people from BAME groups do seek help the services are appropriate, accessible and equipped to meet their needs.

  When recruiting, Community Development Officers should ideally have some level of dementia knowledge as well as the following qualities: confident; organised; flexible; adaptable; good at problem-solving; resilient; independent; and open-minded.

In addition, it is important to recognise that the project will take time to establish, and the amount of preparatory work required will mean that impact and results will not be seen immediately.

Recommendations for the Community Development Officer role

While it is anticipated that some of the following will be incorporated in the final project toolkit, a full set of recommendations has been provided based on the experiences of the Community Development Officers and the learning from the project.

The importance of ground work

In order to deliver appropriate and effective dementia awareness activities, Community Development Officers require a comprehensive knowledge of who they are working with and what they can offer. This requires a significant amount of preparation and time, with a focus on the following key areas:

- **Building a personal knowledge base** – Do all relevant training courses and feel able to ask questions or look for more information to clarify your own knowledge. Find out what resources are available to give to people and make sure you are comfortable with delivering them;

- **Get to know the area** – Understand the demographics of your area and find out about the different BAME communities. See if any lists of BAME community groups already exist of if you will need to create your own. Do not rely on internet searches as there may be a difference between online and physical presence. Take time to walk around the area to see what is actually out there;

- **Start to build relationships and a network of contacts** – Find out who you can work with and use as a contact, rather than potentially duplicating effort or starting from scratch. Useful groups to make connections with include:

  - Local Councils – Adult Services Commissioner, Public Health Officer, Communities Officer, Liaison Officer;

  - Local Clinical Commissioning Groups and GP surgeries;

  - Community Volunteer Services;

  - Religious institutions and centres;

  - Libraries and community centres;

  - Hospitals;

  - Universities and colleges;

  - Carer organisations;

  - Organisations such as Healthwatch.

- **Get to know the people in the local Alzheimer's Society office** – Explain the project to them and learn about what they do. Investigate the possibilities of joint working;

- **Find out about services** – Learn about the services available in the area. A good starting point could be Alzheimer's Society services, or asking a local Dementia Adviser. Having an understanding of the dementia services available will enable you to signpost people, make them aware of what is out there, and give you confidence to answer any questions;

- **Know your starting point** – In order to know if the work you are doing has an impact you need to know what the situation was in your area before you began. This could include dementia diagnosis rates, especially for people

from BAME communities, referral rates to services, and diversity of participants at services such as dementia cafes.

Initial contact and engagement

Making contact with different groups or organisations, whether they are BAME communities or professionals, may require considerable effort and perseverance. Community Development Officers should remember that learning about dementia will not be a priority for many groups and they may encounter negative responses or find there is a need to contact groups on multiple occasions before progress can be made. It might be necessary to try different methods for getting in touch with groups including letters, emails, telephone calls and face-to-face meetings.

Dementia awareness sessions

When planning an awareness session Community Development Officers can minimise potential issues by clarifying and checking practicalities with the group organiser prior to the event. This includes:

- Time and location, including room size and layout;

- Duration of the session, which will help when planning the presentation;

- Anticipated group size as this could affect the type of presentation or the activities used;

- Equipment provision and availability to know whether the Community Development Officer should take their own equipment;

- Language requirements to know whether an interpreter and/or translated resources are required.

It can be useful for Community Development Officers to have a back-up plan available in case the situation they face does not match what they were expecting.

Community Development Officer might consider delivering a joint presentation, for example with an Alzheimer's Society Dementia Support Worker, health care professional, local service provider or project volunteer. Such presentations can provide a different perspective, additional information, or help to bridge the gap between BAME communities and services. Information about local services should be made available during all sessions regardless of who is involved in their delivery.

When planning a session it is useful to have information about the group in question to know if there is anything specific that Community Development Officers should be aware of to help them tailor the session accordingly. However, it is important to remember that every BAME community is different and there can be diversity within a community, so any information should be treated as advice and guidance rather than definitive.

In order to keep sessions relevant and interesting it can be useful to incorporate activities and techniques that make a presentation more interactive. Keeping slides simple and visual with no jargon can also make them easier to understand. Regardless of what has been planned, Community Development Officers need to be flexible and adapt the session as they go along in order to respond to the group's interests and needs at the time.

Follow-up and sustainability

Once a session has finished, it is important to consider appropriate follow-up activities which might include:

- **Keeping in touch** – Shortly after the session the Community Development Officer should get in touch with the group to:
  - o Thank them for their time and interest;
  - o Ask if the group would like further information;
  - o Provide contact details;
  - o Offer to repeat the session in the future for people who were unable to attend or as group membership changes;
  - o Offer to deliver a Dementia Friends session for the group;
  - o Ask if they can provide contacts for other groups who may be interested.

  While these actions may seem simple, they can help to maintain contact with a group and build relationships. This can result in recommendations to other groups, a wider contact network and invitations to community events, which can open up a whole new area of potential contacts;

- **Taking time to reflect** – It is worth reflecting on each session to identify what worked well or not quite as intended, and use it as a learning opportunity for future sessions. Any concerns should be raised with the Project Manager or discussed with other Community Development Officers during peer support sessions as appropriate;

- **Recording the session** – Information about the session should be recorded on the central database to ensure that an accurate picture of engagement activities is available for monitoring and reporting purposes;

- **Sharing information** – If necessary, Community Development Officers can share information about the session with relevant parties. For example, if specific information about a BAME group is discovered or a particular activity resonates with people it should be shared with other Community Development Officers to allow them to make use of it in their work. It should also be incorporated into the toolkit if appropriate.

Working with volunteers

In order to use volunteers effectively, Community Development Officers need a clear idea about how the volunteers will be involved before attempting to recruit them. This should help to minimise the risk of misleading potential volunteers, ensure that volunteers are suitable for their intended role, and consequently make it easier for the Community Development Officers to maximise the value of their input.

Ideally, volunteer training should be delivered through interactive face-to-face sessions rather than via e-learning. The sessions should be held in locations that are convenient for the volunteers to avoid making travel a potential barrier to accessing the training.

Community Development Officers need to be aware of the impact of recruiting and managing new volunteers on their existing workload in order to maintain a balance between the different aspects of their role. Involving volunteers is valuable and worthwhile, but can also be time-consuming for the Community Development Officers.

Summary

Through the substantial efforts of the Project Manager and the Community Development Officers, the Connecting Communities Project has developed a strong knowledge base regarding ways to successfully and effectively engage with BAME community groups and work with volunteers from diverse backgrounds. The project has combined an overarching presentation and an experience-based toolkit to form a standard approach that remains flexible enough to be tailored to meet the individual needs of diverse community groups. This approach creates a robust platform on which further work can be developed. This external evaluation makes key recommendations for maximising the successful development of the project, and others of a similar type, including arrangements for project management and support.

Appendix 1 – Background information

BAME list

The BAME definition used by the evaluation team was taken from the 2011 census[18] and consists of the following communities:

- **White:**
  - Irish
  - Gypsy or Irish traveller
  - Other White

- **Mixed/multiple ethnic groups:**
  - White and Black Caribbean
  - White and Asian
  - White and Black African
  - Other Mixed

- **Asian/Asian British:**
  - Indian
  - Pakistani
  - Bangladeshi
  - Chinese
  - Other Asian

- **Black/African/Caribbean/Black British:**
  - African
  - Caribbean
  - Other Black

- **Other ethnic group:**
  - Arab
  - Any other ethnic group

Existing dementia initiatives

The NHS England 2014/2015 plan for dementia targeted improving diagnosis rates on a regional scale. Presentations about the impact of this work[19] which began in

---

[18] Census 2011, Office of National Statistics, available from http://www.ons.gov.uk/ons/guide-method/census/2011/index.html (accessed 17/07/2015)

September 2014 have shown that between April 2014 and March 2015 dementia diagnosis rates have improved for each of the 32 Clinical Commissioning Groups within London. While the mean improvement was higher for the eight target boroughs (10.3%) than the for the other 24 boroughs (9.7%) there is nothing to suggest that this is related to the Connecting Communities Project, especially as the figures are for dementia diagnosis overall rather than for diagnosis amongst BAME groups. The presentations recognise that multiple factors have been involved in improving rates, including auditing how dementia is coded in patient records and computer systems.

Local initiatives

Croydon Council has developed a dementia strategy in conjunction with statutory and volunteer sector partners within the borough. The strategy recognises the scale of the dementia problem now and it's predicted growth in the future, and has taken it on as a priority for the borough to tackle. In particular BAME communities have been identified as one of the key areas to consider and so were included in the development of the strategy. This was done through consultations taking place between the Croydon BME Forum and members of the BAME community with dementia and their carers. Croydon is already in a fairly strong position due to the Croydon Memory Service, although the vast majority of its referrals are from White British groups.

Redbridge has developed a dementia action plan where increasing diagnosis rates has been set as a high priority. It is unclear if issues affecting BAME communities have been recognised within the plan.

Enfield has its own joint dementia strategy which includes targeting BAME groups in its awareness raising plans and recognises the need to meet the needs of the growing number of people with dementia from BAME communities. It was noted during the project evaluation that Enfield is a well-organised borough with a good internal network.

Newham has a joint dementia strategy which appreciates the ethnic diversity of the borough and the need to improve its services in response. For example, this will include addressing language and communication issues and providing culturally appropriate activities for people with dementia.

Elsewhere in London, the Tower Hamlets Memory Services have focused on cross-cultural dementia diagnosis and how to provide culturally-appropriate dementia assessment and diagnosis. They recognised that there was not an easy solution and

---

[19] London Dementia Strategic Clinical Network (2015). *Paving the way in dementia diagnosis: Lessons learnt and future planning*, available from http://www.londonscn.nhs.uk/event/paving-the-way-in-dementia-diagnosis-lessons-learnt-for-future-planning/ (accessed 17/07/2015)

there needs to be a multi-faceted approach looking at culture and language, local demographics, educating the community, educating GPs and other health professionals, and improving diagnosis tools.

More widely, the 2gether NHS Foundation Trust in Gloucestershire has developed the BME Dementia CQUIN (Commissioning for Quality and Innovation) to focus on delivering BME awareness training to staff working in dementia services, and improving access to assessment, diagnosis and support services for people with dementia and carers from BAME communities.

Borough profiles

Key statistics reflecting the position of the boroughs as they would have been at the beginning of the Connecting Communities Project are provided in Table 3, followed by a brief summary of each borough.

Table 3: Borough statistics

Borough	Overall population[20]	Population aged 65+[20]	BAME population[21]	People with a dementia diagnosis[22]
Croydon	363,378	12.2%	47.5%	44.3%
Enfield	312,466	12.4%	41.2%	39.2%
Hillingdon	273,936	12.8%	42.4%	36.1%
Hounslow	253,957	10.6%	50.2%	50.3%
Lambeth	303,086	7.7%	43.5%	60.2%
Merton	199,693	11.6%	36.5%	39.0%
Newham	307,984	6.7%	72.4%	62.2%
Redbridge	278,970	12.0%	60.7%	39.5%

Croydon

Croydon is the second largest borough in London and a high percentage of its population is aged 65+. Its BAME population is expected to rise significantly by 2021 and although its older population is less diverse than the younger population the size

---

[20] Census 2011, Office of National Statistics, available from http://www.ons.gov.uk/ons/guide-method/census/2011/index.html (accessed 17/07/2015)
[21] Greater London Authority: London Database (2013), available from http://data.london.gov.uk/dataset/london-borough-profiles (accessed 17/07/2015)
[22] Alzheimer's Society (2012). *Mapping the Dementia gap 2012: Progress in improving the diagnosis of dementia 2011-2012*.

of the older BAME population is growing faster than the older White population. People from Asian groups are less likely to be diagnosed with dementia.

Enfield

Enfield contains a high number of people from Turkish, Greek and Albanian communities, many of whom may not be captured by BAME statistics that do not include 'White other'. Enfield also has a high 65+ population.

Hillingdon

A high percentage of Hillingdon's population aged 65+. It is the most linguistically diverse borough.

Hounslow

Hounslow has high Indian and 'Other white' populations but overall its population is relatively young.

Lambeth

Lambeth has a complex ethnic mix and its Black Caribbean and Black African 60+ populations are expected to increase more than other ethnic groups in the next ten years.

Merton

Merton is the smallest target borough and is expecting its 65+ population to increase by 11% between 2011 and 2017. Its older population is less diverse than the people in the younger age groups.

Newham

Newham is the most ethnically diverse borough and is also linguistically diverse. Although over 40% of its population is Asian, no single BAME group accounts for more than 14% of the population. The borough has a young age profile with just 6.7% of its population aged 65+, 55% of whom are White.

Redbridge

Over half of the Redbridge population is non-White, with 42% being Asian or Asian British.

Appendix 2 – Annual report project summary and recommendations

Project summary

The Alzheimer's Society was awarded funding by the Department of Health to undertake an innovative three-year pilot project entitled the Connecting Communities project. This project has a focus on engaging volunteers from Black and Asian Minority Ethnic (BAME) communities in order to design and deliver activities raising dementia awareness across eight London boroughs. The evaluation for this project consists of two parts: an internal evaluation carried out by the Alzheimer's Society and an external evaluation carried out by the Association for Dementia Studies (ADS). This report presents the findings from the first year of the external evaluation of the Connecting Communities project.

A number of evaluation methods were developed to measure the impact of the Connecting Communities project against the following four outcomes:

Outcome 1: Increased engagement with BAME communities and community-specific dementia health care providers;

Outcome 2: Increased dialogue between BAME communities and the Alzheimer's Society and other stakeholders;

Outcome 3: Increased dementia awareness and knowledge of dementia care services in BAME communities;

Outcome 4: Increased understanding amongst professional groups of dementia-specific issues faced by BAME groups.

The evaluation applied a mixed methods approach including: questionnaires for organisations; semi-structured interviews with the project manager and volunteering officers; focus groups with the key stakeholders; and observations and feedback from participants of the dementia awareness sessions delivered by the Alzheimer's Society.

Results have indicated that the Connecting Communities project is starting to increase engagement with BAME communities and community-specific dementia health care providers. Since the dementia awareness sessions have been delivered as part of the Connecting Communities project, the number of people accessing dementia-specific services from a BAME background has begun to increase.

Increased dialogue between BAME communities and the Alzheimer's Society is seen in the finding that the project has exceeded the target of reaching 1,950 people

within the first six months of the project. The dementia awareness sessions are also having a snowball effect within BAME communities, evidenced in the feedback given by participants following the sessions who were hoping to share information with friends and relatives, or who had been encouraged to attend a session by another member of their community. BAME groups are also starting to approach the Alzheimer's Society for awareness sessions as they recognise that dementia is relevant to them. The Connecting Communities project has generated valuable information on how best to approach, engage and work with groups from different BAME communities. The key stakeholders involved recognise the need to ensure that these findings are implemented in dementia policy and practice and equality and diversity strategies.

Results also indicated increased dementia awareness and knowledge of dementia care services in BAME communities, with some organisations having done further dementia-related activities to encourage awareness within their target groups since the dementia awareness sessions. All feedback about the sessions has been very positive and organisations would recommend the sessions to other similar community-based groups as they were considered very useful.

Whilst the Connecting Communities project has a core focus to raise dementia awareness within BAME communities, the experiences and lessons learnt from the intervention can help increase understandings of dementia-specific issues faced by BAME groups amongst other professional groups. This highlights the importance for dissemination of the findings from the Connecting Communities project and the role of the key stakeholders for ensuring this information is translated into dementia policy and practice and equality and diversity strategies. Results from the questionnaires for organisation did indicate an awareness of some of the dementia-specific issues faced by BAME groups.

Recommendations

Based on the findings from this external evaluation, we make recommendations to further enhance the success of the Connecting Communities project in relation to the project organisation, the dementia awareness sessions and sustainability. As the Connecting Communities project is a pilot project, it is anticipated that these areas will also develop organically as the project continues.

Project organisation

The evaluation to date has highlighted some of the skills required by the Volunteering Officers. They should:

- Have good organisational and communication skills;

- Have a good level of dementia knowledge to enable them to answer questions and adapt presentations as necessary;

- Have at least some knowledge of the wider medical and social context of dementia;

- Know where to signpost people for further information.

In terms of the volunteers, their role may need to be reassessed to ensure that there is a common understanding between the Project Manager, Volunteering Officers and the volunteers themselves. Recruitment strategies may also need to be reconsidered as the role differs from expectations of a volunteering role. There is also no clear distinction between the community engagement champions and the community engagement volunteers and whether this has any impact for the delivery of the Connecting Communities project.

To date, the main focus of the Connecting Communities project has been on delivering awareness sessions to community groups. There has been limited evidence of the Volunteering Officers having contact with professionals or dementia-specific services to address the issues faced by BAME groups, suggesting that this could be an area to focus on in the future. In order to do this, the information and support required by the Volunteering Officers would need to be investigated. One option for improving engagement between professionals and the community could be to include professionals in the awareness sessions where appropriate.

The awareness sessions

Delivering awareness sessions in person and providing information in a visual format are considered to be two key ways of helping people from a BAME background to learn about dementia, so should be taken into account when working with such communities. Also, to ensure that sessions have the maximum impact the content and style of any presentations should be reassessed to keep them simple and straight forward. Observations of the awareness sessions conducted by members of the external evaluation team highlighted an inconsistency in the content, and order of information being delivered to participants. Based on observations of what worked well, the following order of key points is recommended:

- What dementia is;

- It's not a normal part of ageing;

- Types of dementia including where Alzheimer's Disease fits in (but possibly not using the 'umbrella' analogy);

- Symptoms of dementia (and other possible causes/reasons);

- Importance of timely diagnosis;

- Risk factors and reduction;

- Support available for people with dementia and their carers.

Sessions should remain clear that there is no cure, but focus on the positive aspect of living well with dementia.

Sustainability

Looking at the wider context around the project is also important, such as dissemination of the findings, increased dialogue with stakeholders, and working to ensure that wider services support rather than undermine the work being carried out by the Connecting Communities project team. As indicated by the key stakeholders, the project should be sustainable within BAME communities rather than ending after the awareness sessions. We support the suggestion that the BAME groups and organisations join the Dementia Action Alliance to give them a longer term goal and a support network for supporting people with dementia and their families to live well.

Due to the success of the project having exceeded the target number of people from BAME communities within the first year, there may be possible capacity issues. Priority should therefore be placed on developing the toolkit for delivering dementia awareness sessions in BAME communities for future volunteers to use. The toolkit needs to be easily accessible, adaptable, and easy to understand. It should include information about the best ways to approach and engage with the various communities as experienced as part of the project.

Appendix 3 – Session observation template

Alzheimer's Society Dementia Awareness Session – Overview and observations	
BASIC INFORMATION	
Location:	**Date:**
Leaders:	
Observers:	
Preparation:	
Attendees:	
Language:	
THE SESSION	
Session:	**Observations & comments:**

GENERAL/ADDITIONAL COMMENTS

FEEDBACK