



Evaluation of
**Dementia
Projects for
Minority Ethnic
Communities**
Final Report

3 Boroughloch Square,
Edinburgh EH8 9NJ
T: 0131 667 2919
E: admin@blakestevenson.co.uk
www.blakestevenson.co.uk



Life Changes Trust
Evaluation Report
October 2020

life 
changes
trust
Creating better lives.

CONTENTS

Chapter	Page
1. Introduction and background	1
Context	1
Overview of projects funded by Life Changes Trust’s Minority Ethnic Communities and Dementia programme	3
Evaluation aims and approach	6
Structure of the report	7
2. Minority Ethnic Communities and Dementia Programme: project delivery	8
ACVO: Widening Dementia Support for People from European Ethnic Minority Backgrounds	8
MECOPP: Chi Sin Chi Mei (CSCM) project	12
CSREC: Dementia and Care in our Communities project	26
REACH: Community Health Project	33
3. Summary of outcomes delivered and recommendations	45
Introduction	45
Progress against project outcomes	45
Recommendations	49

1. Introduction and background

In March 2019, the Life Changes Trust (the Trust) commissioned Blake Stevenson Ltd to evaluate the Minority Ethnic Communities and Dementia programme, which funded four projects to support people from minority ethnic communities who are living with dementia and unpaid carers¹.

This is our final report, which discusses the impact of the four funded projects over each of their respective funding periods. Our report is based on evaluation activities we have conducted and information and data collected by the four projects.

Context

Across the UK, there are more than 25,000 older people from minority ethnic communities living with dementia.² This number is expected to grow to nearly 50,000 by 2026, and over 172,000 by 2051, a seven-fold increase in 30 years, compared to only a two-fold increase for the general population of people living with dementia in UK in the same period.³ Improving care and support for people living with dementia and those who care for them is a major priority for the Scottish Government.

¹ Throughout this report, when we refer to ‘carers’, unless otherwise stated, we are referring to unpaid carers, family members and friends who care for people living with dementia.

²<https://www.scie.org.uk/dementia/living-with-dementia/bme/>

³https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf

However, the experiences of individuals from minority ethnic communities living with dementia are vastly different to the mainstream and are affected by distinct barriers, specific to each minority ethnic community.

Currently, accurate data on people from minority ethnic communities living with dementia at either the Scottish or UK levels is not available, making it difficult to conduct accurate needs assessments or estimate demand for services.⁴

Amongst many minority ethnic communities, dementia is not known by a specific term and knowledge and understanding of the disease is limited. Lack of understanding and awareness of dementia creates many barriers for individuals accessing timely support, often resulting in individuals receiving late diagnoses, and families trying to cope for longer without support. Many families from minority ethnic communities may resist engagement with social and health care services as they fear discrimination or perceive services to be culturally inappropriate. As a result, people from minority ethnic communities living with dementia are sometimes inappropriately treated and unpaid carers are left without guidance or support.

The UK All-Party Parliamentary Group on Dementia conducted an investigation into the experiences of people from minority ethnic communities living with dementia in 2013.

⁴https://www.alzscot.org/sites/default/files/images/0003/0229/Spotlight_on_Dementia_and_Equalities.pdf

It found evidence that it is likely that dementia is more common amongst minority ethnic communities as a result of the prevalence of high blood pressure, diabetes, stroke and heart disease, which are all common risk factors for dementia. The inquiry also found that families from minority ethnic communities living with dementia struggle with little or no support from the NHS or local government, as specialist services are too few and far between, and that there is an urgent need to increase awareness of dementia among minority ethnic communities.

The recent publication, *Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities: Key Issues and Strategies for Change*⁵ enriches the limited evidence that is available. It provides a practical account of the impact of living with dementia for individuals and families from minority ethnic communities. It identifies issues for specific communities as well as common challenges and barriers like interpretation and translation, e.g. finding a translatable equivalent of the vocabulary of dementia services, developing appropriate reminiscence materials, and the limited consideration of relevant services for the later stages of dementia and end of life care.

Overview of projects funded by Life Changes Trust's Minority Ethnic Communities and Dementia programme

The Trust is committed to improving the lives of people living with dementia, by enhancing their quality of life, wellbeing, empowerment and social inclusion.

⁵ Truswell, David (ed) (2019), 'Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities: Key Issues and Strategies for Change', Jessica Kingsley Publishers

The Trust has five key priorities guiding this work, uniting in an aim to support better lives for all people living with dementia.⁶

In April 2018, the Trust made awards totalling almost £200,000 to four projects, funded to work with people living with dementia and unpaid carers in minority ethnic communities for up to two years. All four projects started in May 2018, and all had various end dates that reflected the focus of their work and, in some cases, extensions to their funding period. The Trust was keen to learn about the impact of the projects and what helps to improve the lives of people from minority ethnic communities who are living with dementia.

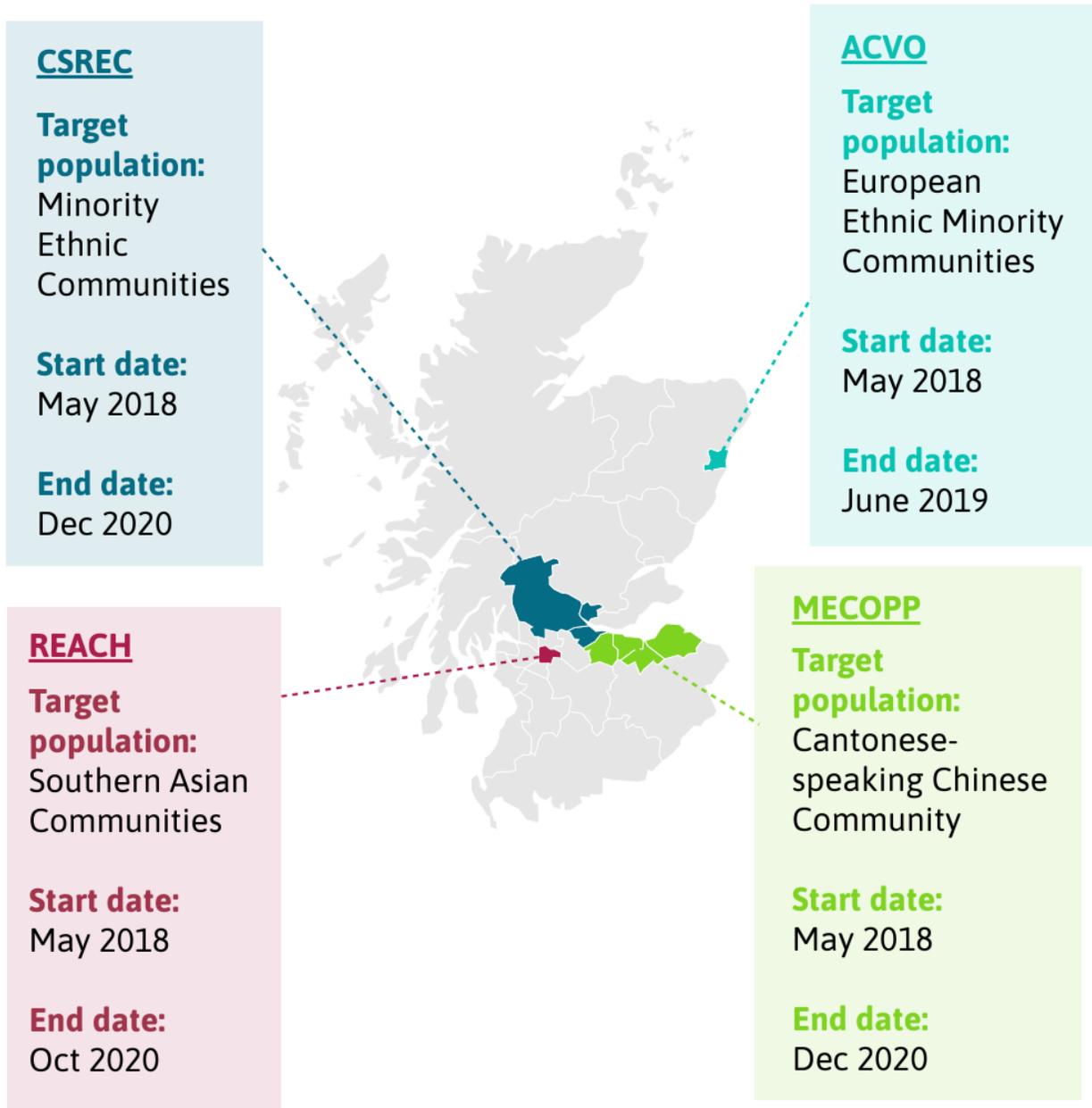
Overall, the aim was that the projects would lead to:

- increased engagement with people from minority ethnic communities living with dementia and unpaid carers ;
- an increased number of culturally relevant services in Scotland for people from minority ethnic communities living with dementia and unpaid carers;
- a change in perceptions of dementia and reduction in stigma around it within minority ethnic communities; and
- deeper learning about the needs of people living with dementia and unpaid carers from these communities, leading to an increased understanding about the particular issues that people from certain ‘protected characteristic’ groups may face when they are affected by dementia.

⁶<https://www.lifechangestrust.org.uk/sites/default/files/publications/Dementia%20Programme%20Strategy%20Summary.pdf>

The four projects worked in nine local authority areas across Scotland as displayed in Figure 1.1.

Figure 1.1: Location and target population of the four projects



Evaluation aims and approach

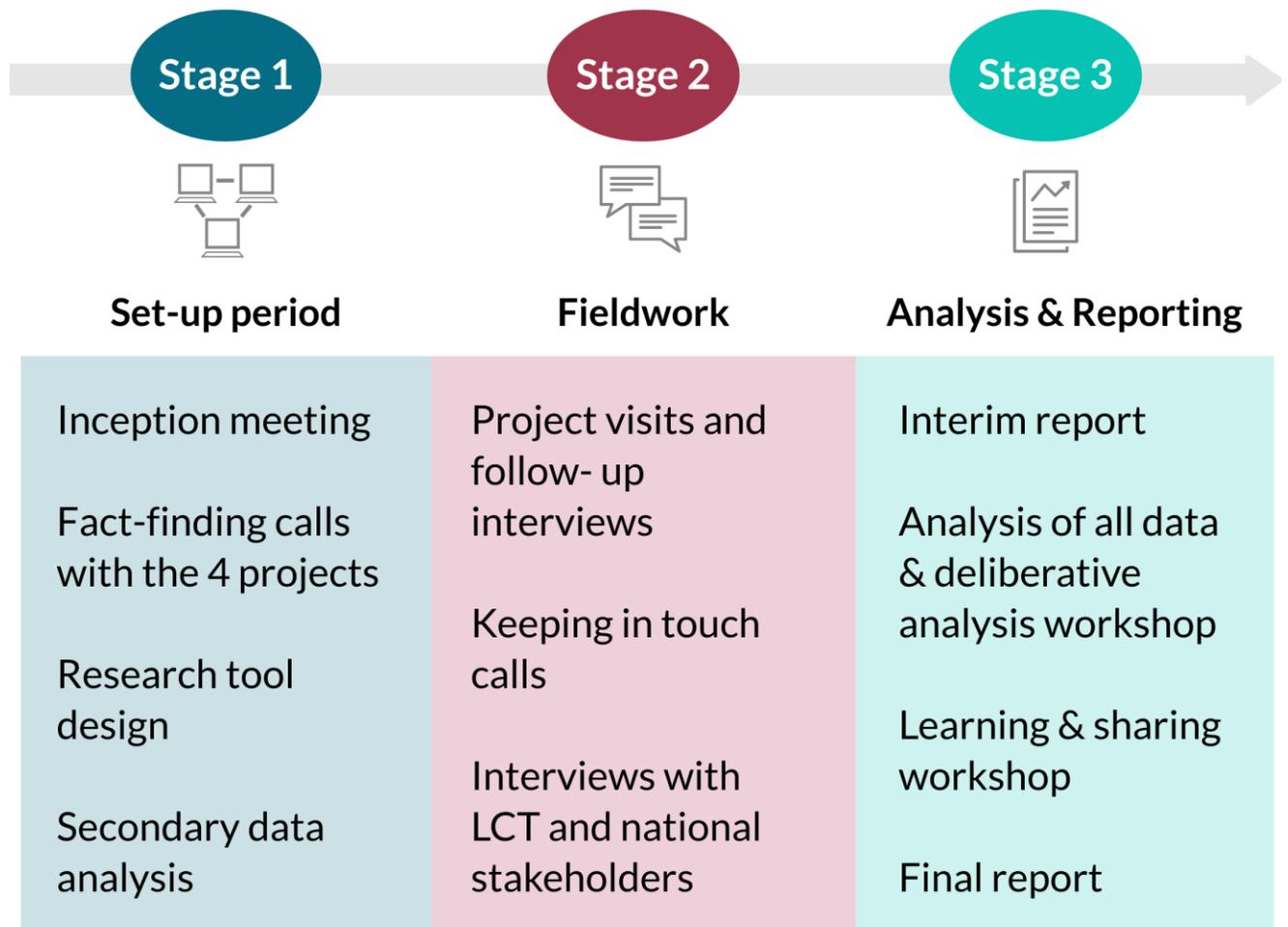
The evaluation aimed to determine:

- the extent to which the projects created better lives for people from different minority ethnic communities living with dementia and unpaid carers;
- any barriers and challenges that the projects faced and how they, where possible, overcame them;
- the extent to which the projects provided short, medium and long-term post-diagnostic support (PDS) for people from minority ethnic communities living with dementia;
- the extent to which the projects worked in partnership and any significant benefits this partnership working brought;
- the likelihood that these projects will be sustained in the long term; and
- how the projects have contributed to deeper learning about what helps to improve the lives of people from minority ethnic communities living with dementia, and how this learning can be shared more widely.

To address the evaluation requirements, we gathered information and evidence through: in-depth interviews with project leads, project staff, community groups and local stakeholders; observation of awareness-raising sessions and other activities delivered by the projects; and analysis of data collected and resources created by each project.

Figure 1.2 summarises our methodology.

Figure 1.2: Methodology



Structure of the report

In the next chapter we reflect on the delivery of each of the four projects, including services provided by each project, challenges experienced, and the impact of the projects. In Chapter 3 we analyse the projects’ progress against overall outcomes and present some recommendations informed by the learning from the evaluation.

2. Minority Ethnic Communities and Dementia Programme: project delivery

Aberdeen Council of Voluntary Organisations (ACVO): Widening Dementia Support for People from European Ethnic Minority Backgrounds

Local context and the approach to the service

ACVO is the third sector interface for Aberdeen City, and works to develop, involve, represent and support voluntary, charity and social enterprise organisations in Aberdeen. ACVO used Trust funding to work with individuals from European Ethnic Minority (EEM) backgrounds who are living with or showing symptoms of dementia to provide them with information on what kind of dementia support is available in Aberdeen, and an opportunity to share their experiences and challenges in getting support. The project's primary aims were:

- to support Aberdeen becoming a city where people, regardless of background, are supported to live independent and fulfilling lives;
- to support people from EEM backgrounds in the central locality to be able to make the best use of the dementia support available across the city; and
- to support people living with dementia from EEM backgrounds to live independently and be included in the community.

ACVO decided to focus on EEM communities in Aberdeen because they were a well-established and well-represented group in the city but had no presence in dementia support services.

To initiate contact, ACVO attended locations where people from EEM communities tend to congregate such as local churches, community centres, restaurants and hairdressers, and where ACVO could identify people living with dementia.

Challenges

The main challenge ACVO faced during the life of the project was the lack of engagement from people from EEM backgrounds living with dementia. Despite their efforts, which included liaison with the Dementia Link Worker, the project was not able to identify or engage any people from EEM backgrounds living with dementia in the city and, as a result, the project staff refocused their efforts to consider the issues/potential reasons for the non-engagement with health and social care services and to look at awareness-raising amongst communities and practitioners.

As a result, evaluation activities instead focused on interviews with the three stakeholders identified by the project, and with ACVO staff, including the Dementia Project Worker and the Partnerships Manager.

Resources created

Using this refocused approach, the project identified the need for resources to assist those living with dementia and those providing support and this work was undertaken in the final six months of the project. To mark the end of the project, in, ACVO launched two dementia toolkits⁷. One was aimed at [EEM communities](#) looking to access support for a person living with dementia and this was translated into Polish, Russian and Spanish.

⁷ <https://acvo.org.uk/new-toolkits-for-ethnic-minorities-with-dementia/>

The other was designed for [health and social care practitioners](#) to help them engage more effectively with people from an EEM background living with dementia.

The toolkit for communities provides general guidance and practical advice for families and unpaid carers of people living with dementia. The toolkit for practitioners focuses on how dementia services should be tailored to more effectively support people from EEM communities. The diagram below summarises the content of both toolkits.

Figure 2.1: ACVO dementia toolkits – contents



Toolkit for communities

- ✔ Strategies for living well with dementia
- ✔ Avenues for seeking support
- ✔ Guidance on keeping healthy
- ✔ Overview of the diagnostic process
- ✔ Transport support
- ✔ Links to core services such as Alzheimer Scotland
- ✔ Details of local dementia support such as Living Well Cafes, VSA Carers Support, and Disabled Person's Housing Services Aberdeen



Toolkit for practitioners

- ✔ Barriers and challenges faced by EEM communities
- ✔ Guidance on engaging and communicating with EEM communities
- ✔ Checklist to measure effectiveness of engagement with EEM communities
- ✔ The importance of independent advocacy

The interviews with stakeholders identified the value of these toolkits. Stakeholders observed that the toolkit is contributing to “growing awareness and recognition” of dementia and the support available among EEM communities.

They also noted it would help to increase understanding of the needs of EEM communities among health and social care staff, and that it is helping to ensure that the needs of EEM communities are recognised in future service provision.

Summary

The ACVO project concluded in June 2019. Since then, ACVO has continued to publicise and distribute the toolkits for the community and practitioners across the city and, as a result of this work and their previous dementia project, ACVO is continuing to contribute to the development of the local dementia strategy in Aberdeen.

Minority Ethnic Carers of Older People Project (MECOPP): Chi Sin Chi Mei (CSCM) project

Local context and the approach to the service

MECOPP was established in 1997 when it published its first substantive piece of research into the needs of unpaid carers from minority ethnic communities, highlighting the difficulties they faced in accessing mainstream statutory and voluntary sector services. In 2000, MECOPP began working with and providing dementia support services to the Chinese community in the NHS Lothian Health Board area (Edinburgh, West Lothian, Midlothian and East Lothian local authority areas).

Hong Kong was a British colony from 1841 until 1997, aside from the few years of Japanese occupation from 1941 until 1945. After Hong Kong was received back under British administration in 1945, the post-war economy impacted many individuals' ability to make a living.

Consequently, many families decided to exercise their right of abode and relocated to the UK to start a new life.

These new migrants learnt English as a second language; however, project staff reported that a language barrier still remains and to this day persists as one of the biggest challenges for Chinese individuals in accessing mainstream medical services in the UK.

Project staff noted that, currently, many people in Chinese communities in Lothian and across Scotland still prefer to seek medical advice in Hong Kong for serious conditions, such as dementia. They believe that they cannot gain sufficiently detailed understanding of their condition through using mainstream services in Scotland due to language barriers. Many do not wish to rely on interpretive services for diagnosis of a serious condition, as they do not trust the quality and accuracy of the interpretation.

MECOPP staff observed that dementia remains heavily stigmatised within Chinese communities due to a lack of understanding and acceptance of dementia as a serious medical condition. The Chinese word for dementia directly translates to mean ‘crazy’ or ‘chaotic’. This stigma can lead to individuals refusing to seek medical treatment, or individuals isolating themselves from their family and community in order to hide their symptoms.

In 2018, MECOPP launched the CSCM project with the aim of providing dedicated support to both individuals in the Chinese community in Lothian with a diagnosis or suspected to be living with dementia and unpaid carers. The project provides a Dementia Support Worker to undertake awareness-raising and educational activities to increase community knowledge and understanding of dementia.

The support worker also provides dedicated information, advice and support to people who are in the process of being diagnosed or who have a diagnosis of dementia.

Figure 2.2 details the list of services and support offered by the CSCM project.

Figure 2.2: Chi Sin Chi Mei project services



Available Support Services

- ✔ Assist in understanding dementia and managing symptoms
- ✔ Assist with communication with health and social work professionals
- ✔ Assist to plan for future decision making and support needs
- ✔ Facilitate access to a range of support services
- ✔ Support people living with dementia to maintain or regain community connections
- ✔ Enable people living with dementia and their families, and unpaid carers to be fully informed and plan their own pathway through dementia
- ✔ Support people living with dementia to access peer support

Implementation of the project

MECOPP used its project funding to recruit a Dementia Support Worker (DSW) dedicated to working with the Chinese community in Lothian. The DSW spent their first few months building their knowledge of dementia and commenced promoting the project throughout the health and social care community in Lothian. The DSW identified eight people diagnosed with dementia and three people suspected of living with dementia, and met with unpaid carers to identify support needs.

However, this DSW left the post after four and a half months as they returned to higher education. MECOPP was able to fill the post with a second DSW in November 2018. They were able to re-establish contact with all of the initial service users, however, unfortunately three of the people living with dementia had passed away by this point.

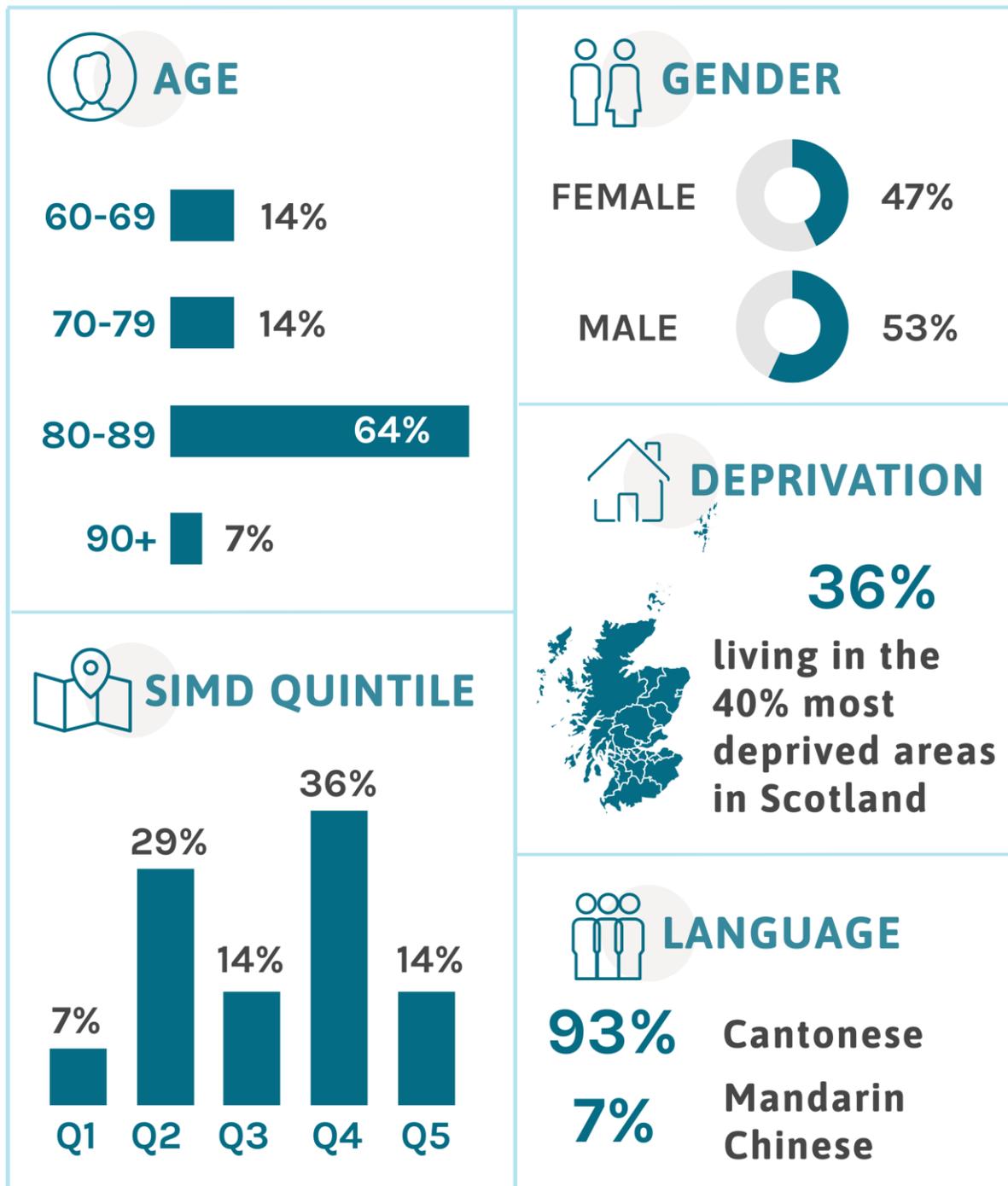
Client profile

Over the life of the CSCM project so far, it has received 16 referrals, 14 of which took up the offer of support. MECOPP is currently providing support to eight service users, providing intensive support to five with diagnoses of dementia, two with no diagnosis, and assisting one through the diagnostic assessment process.

All but one of the referrals received by the project are Cantonese-speaking Chinese individuals, with a few also speaking Hakka, and one Mandarin Chinese speaker. All of the service users were born in Hong Kong and migrated to the UK while Hong Kong was still under British administration.

Figure 2.3 provides a breakdown of profile data for the project’s service users.

Figure 2.3: MECOPP service user profile data



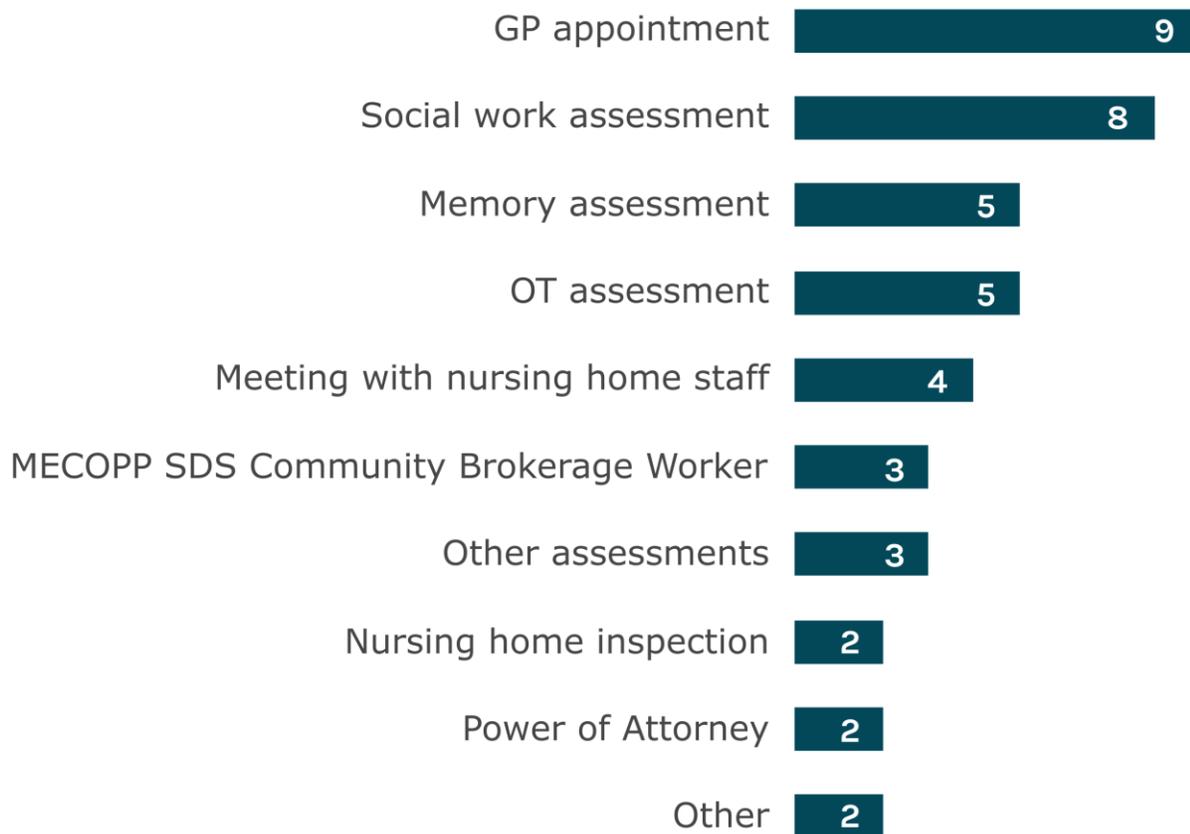
Support provided

Intensive support

When a referral is made to MECOPP, the DSW guides the individual and their family through the dementia diagnostic process, including helping them to book diagnostic appointments. They will then attend GP appointments, tests, and other medical appointments with service users and their families, providing language and emotional support.

If the person living with dementia requires a referral to a social worker, the DSW will help them to arrange their appointment and attend the social care assessment with them to provide language support. The DSW also provides language and general support for service users undergoing occupational therapy assessments, as well as assisting service users to submit applications for care at home equipment. One individual received help from MECOPP in applying for funding to install altered bathroom equipment for her husband who is living with dementia.

Figure 2.4 details the types and number of appointments that the MECOPP DSW accompanied service users to.

Figure 2.4: Appointments attended by MECOPP DSW

[Dementia awareness-raising sessions](#)

The CSCM project's second core offering was a series of dementia awareness-raising sessions delivered to the Chinese community in Lothian. These sessions provided a basic end-to-end overview of dementia, from recognising early symptoms to post-diagnostic support services. Since November 2018, MECOPP has delivered five awareness-raising sessions, attended by a total of 105 individuals. Attendees were generally older couples and single older people accompanied by their children. The sessions explored the different names dementia may be known as in Hong Kong, mainland China and Taiwan, and presented statistics on the prevalence of dementia across each Chinese region and the UK.

The sessions also covered early symptoms of dementia such as memory loss and provided a comparison of the aging process for people living with and without dementia. During sessions, the DSW emphasised the importance of early diagnosis and provided attendees with a list of support services available in Lothian, as well as what services MECOPP is able to provide.

[Support for unpaid carers](#)

MECOPP aims to provide holistic support, including less formal services such as emotional support for family members and unpaid carers. Throughout the life of the CSCM project so far, MECOPP has provided support to 14 unpaid carers. Family members and unpaid carers of Chinese people living with dementia often speak English as a second language, and this, coupled with the emotional toll of caring for loved ones living with dementia, can result in feelings of loneliness and isolation. The DSW found that although family members and unpaid carers were able to have simple conversations in English as part of their day-to-day life, being able to hold a detailed conversation with someone in their native language about dementia provided immense emotional relief and support.

[Challenges](#)

The main challenge faced by MECOPP in supporting Chinese people living with dementia is the lack of Cantonese-speaking workers in mainstream dementia support services. The very limited pathways for Hong Kong citizens to migrate to the UK since the right of abode ceased mean there are very few Cantonese speakers in core services such as GPs, befriending services and dementia cafés.

The effectiveness of current diagnostic tests for dementia has been undermined by a common misconception that Mandarin Chinese is the main language spoken by Chinese communities in the UK, as well as a lack of understanding of the stark differences between Mandarin Chinese and Cantonese.

The Memory Assessment and Treatment Service (MATS) in Lothian uses a questionnaire from mainland China, based on Mandarin Chinese, as its standard assessment tool for all Chinese patients. Although Mandarin and Cantonese use the same Chinese script, these languages often use completely different names to refer to common objects. For example, a tomato is known as ‘xi hong shi’ in Mandarin, and ‘fang qie’ in Cantonese.

When an interpreter reads out Chinese script from the questionnaire that has been directly translated from Mandarin to Cantonese, although Cantonese speakers will recognise the individual words, they will either not understand what the words mean or will not attribute the same meaning to them. Some of the questions in the questionnaire are also culturally inappropriate as they are based on a Mainland China context. For example, the questionnaire may ask individuals to recite an address in Beijing. However, addresses in Mainland China are written in a different format to addresses in Hong Kong, which are based around the British format. MECOPP’s DSW found that service users often struggled to respond to these questions, not due to their cognitive ability, but because they did not understand the wording.

Language barriers also presented an additional challenge for service users accessing mainstream services. The DSW noted that some nursing homes had acquired image cards to assist communication between service users who did not speak English and nursing home staff.

However, when staff reviewed the image cards with a service user, they found that they only understood a small number of the cards, as they were only relevant in a UK context. For example, the image card for ‘shampoo’ depicted a bottle of Wash & Go, however, for many service users, the image just represented a green bottle, instead of shampoo. Another nursing home worker downloaded a translation app to assist with communication, however, the app only pronounced translations in Mandarin Chinese, not Cantonese.

In addition, MECOPP’s DSW noted that current signposting services in Lothian are ineffective, as service users cannot use mainstream services due to language and cultural barriers. The DSW stated that they have not been able to find a single Cantonese speaker working in either befriending services or as a home care assistant.

MECOPP staff reported that mainstream services in Lothian are taking a reactive approach in adjusting their service offerings to support minority ethnic communities. MECOPP approached one dementia café to request more diversified foods to be served to attract people living with dementia from minority ethnic communities and which would help them feel more comfortable to use the service. However, the dementia café stated that they would introduce different foods only after they see an increase in the amount of regular service users from minority ethnic communities.

Summary

MECOPP has received a funding extension until December 2020 and the DSW will continue to provide intensive support to all service users until then.

As the only organisation providing dementia support services to Chinese communities in Lothian and with the Chinese community in the area growing older, MECOPP expects the number of referrals of people living with dementia to increase. During November 2018 to October 2019, MECOPP received 16 referrals. The DSW would like to continue to attend every assessment and appointment with each service user to provide advocacy and language support. However, under their current funding, the DSW works 24 hours a week and as the demand continues to increase, they will not be able to meet everyone's needs and provide this level of intensive support.

To help combat the lack of Cantonese speakers in Lothian, MECOPP is considering setting up volunteering programmes for befriending groups. MECOPP would like to recruit Cantonese-speaking individuals in Lothian and provide them with training on how to engage with people living with dementia. However, MECOPP has limited capacity to implement this programme, and would require additional resources and funding to do so.

Case studies

As part of providing support to their service users, and their families and unpaid carers, MECOPP compiled two detailed case studies of the progress made by the person living with dementia from diagnosis to receiving support from MECOPP.

These are presented in Figures 2.6 and 2.7, and Figure 2.5 presents information about the declining number of Cantonese speakers in Scotland.

Figure 2.5: The decline of Cantonese speakers in Scotland



Figure 2.6: Case study 1 – Mr and Mrs Chan

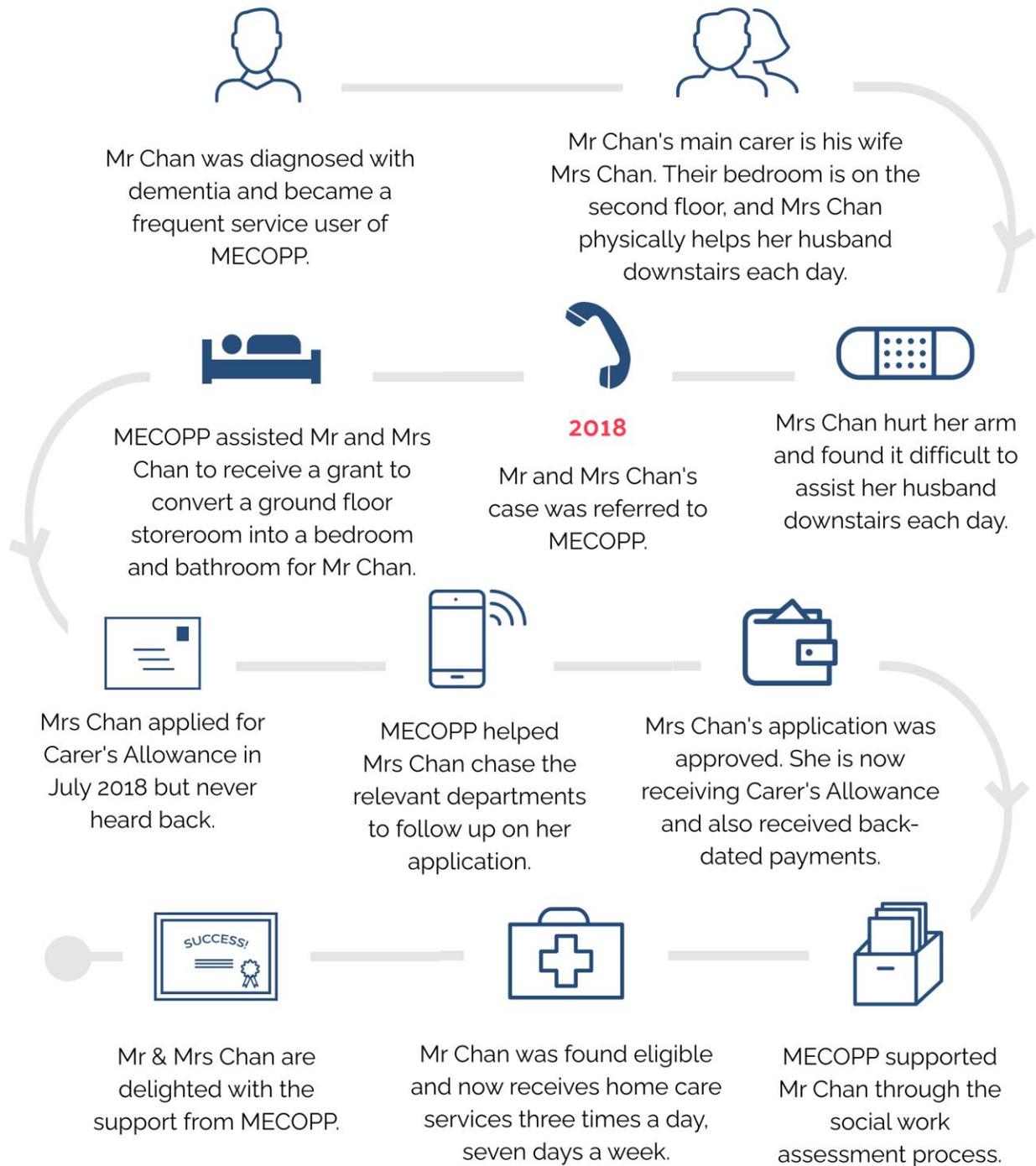
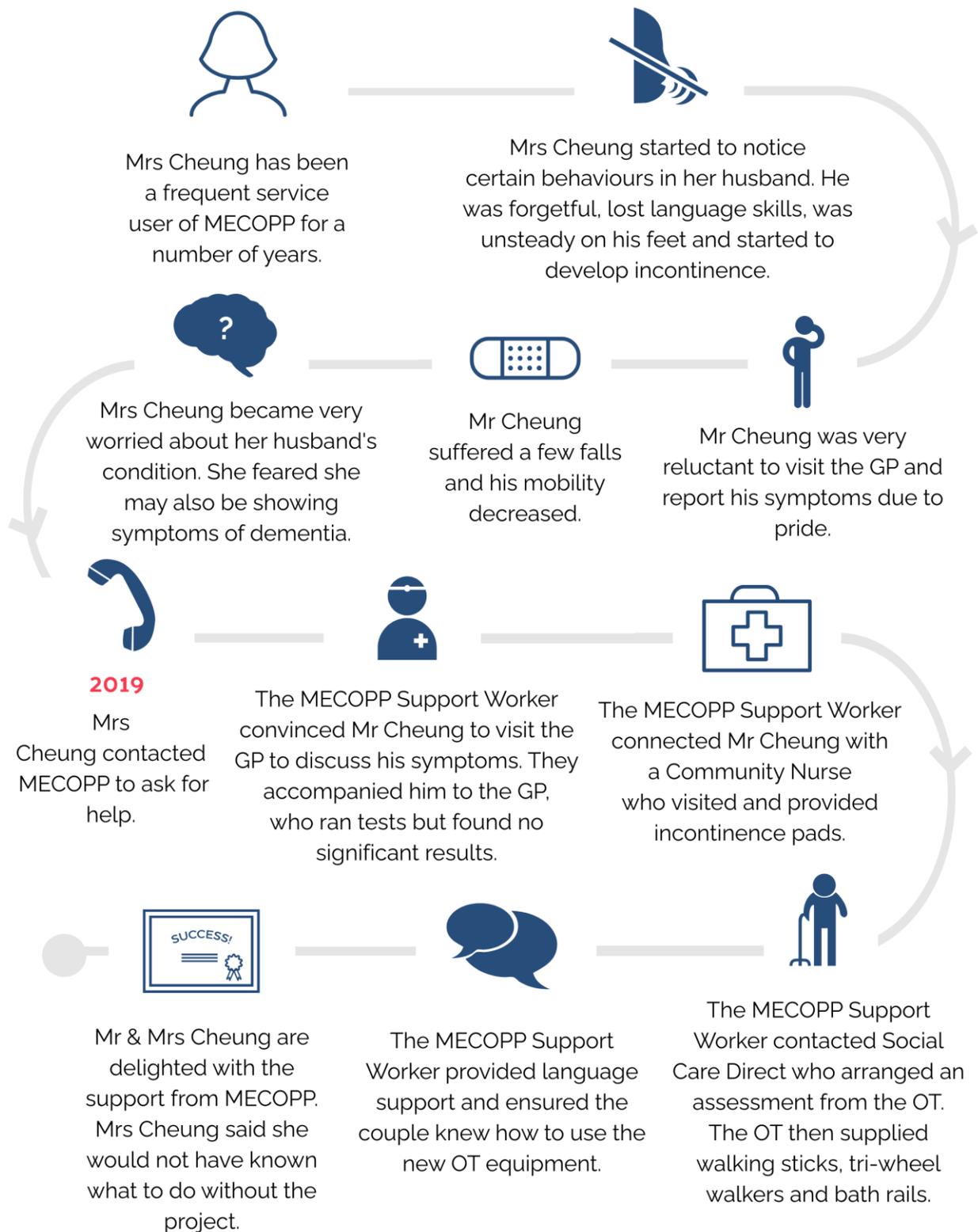


Figure 2.7: Case study 2 – Mr and Mrs Cheung



Central Scotland Regional Equality Council (CSREC): Dementia and Care in our Communities project

Local context and the approach to the service

CSREC has been in existence for 36 years. It is based in Falkirk, but works across all of the NHS Forth Valley Health Board area (Falkirk, Stirling and Clackmannanshire local authority areas). CSREC focuses on work with the aim of eliminating discrimination in all its forms, reducing inequality, and promoting a culture of human rights.

CSREC also delivers several other services and projects across the Forth Valley area, like Equality in the Community and Volunteering for All, through an Equality Engagement Officer and Community Link Officers who work with various equality groups and minority ethnic communities in the area.

There are many minority ethnic communities dispersed across the three local authority areas that CSREC covers and so CSREC's focus and engagement must reflect this diversity. The dementia project aims to reach all minority ethnic communities. This includes the Pakistani and South Asian, Chinese and East Asian, Polish and East European, African and Caribbean, Arab and Gypsy and Traveller communities, religious minorities, and others. The project's aims have evolved over time, however the initial focus of the work was to:

- enable dementia service providers to enhance their understanding of the specific support needs of people from minority ethnic communities living with dementia and their unpaid carers;

- assist understanding of barriers experienced by people from minority ethnic communities living with dementia and unpaid carers in accessing dementia support services; and
- provide examples of good practice in supporting people from minority ethnic communities living with dementia and unpaid carers and increase understanding of the extent and impact of dementia on their lives.

Implementation of the project

The CSREC project is an awareness–raising project rather than a service delivery one. The rationale for this is that the local minority ethnic communities are too thinly spread across the area to provide a comprehensive service. The awareness–raising has been delivered in two main ways. Firstly, by raising awareness amongst specialist dementia service providers of the barriers faced by people from minority ethnic communities living with dementia in order to make these services more inclusive in the future. Secondly, and simultaneously, CSREC has raised awareness and challenged preconceptions about dementia amongst minority ethnic communities.

Services delivered

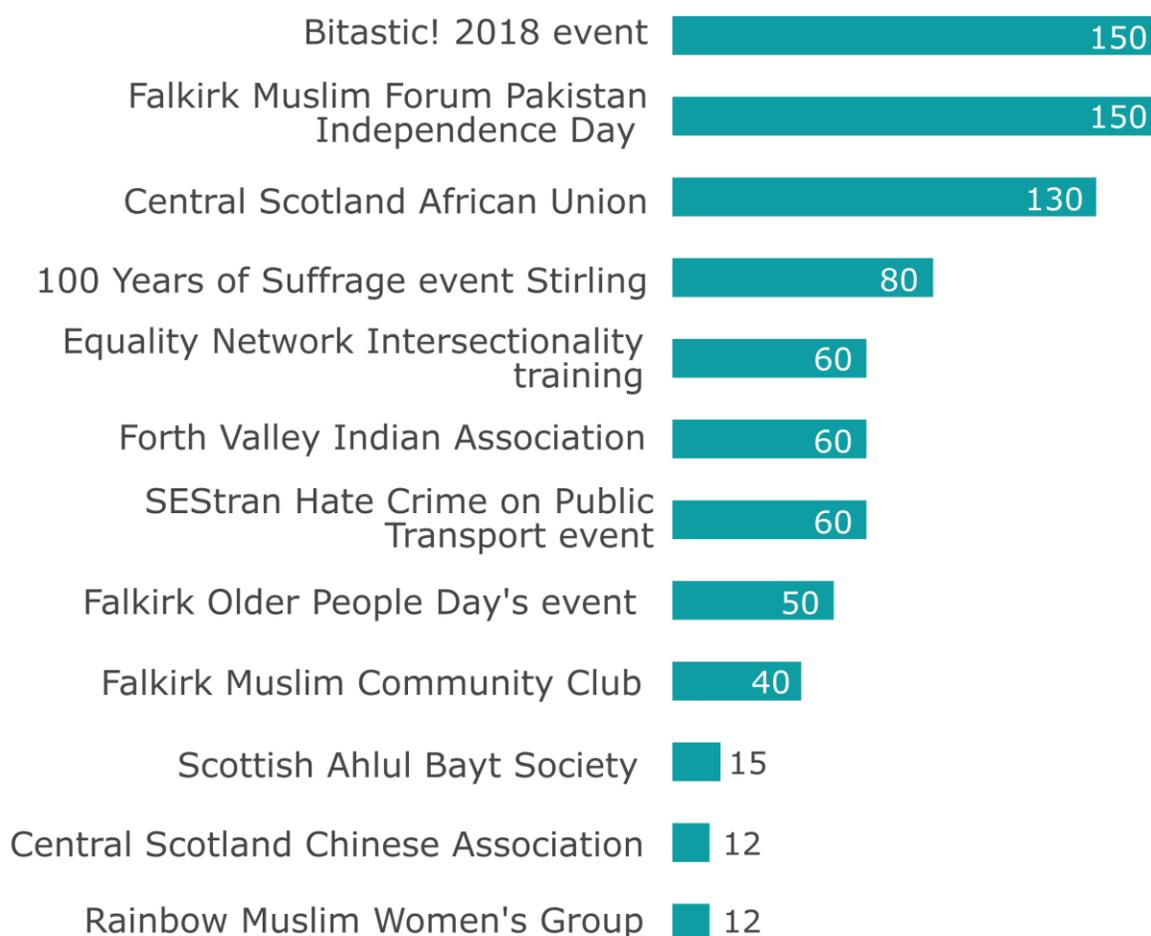
Dementia awareness–raising sessions

In its engagement with people from minority ethnic communities, the nature of the support and advice delivered has been flexible so that the project could respond to the needs of those being supported. As part of this, CSREC has delivered a series of awareness–raising sessions, covering their rights as unpaid carers, information to help them deal with practical and emotional issues, and case studies to help them understand dementia–related behaviours. The sessions have also been tailored to be

culturally specific to each group. CSREC has been able to deliver several well-attended sessions, including a session in partnership with the Central Scotland African Union with 130 attendees, and a session with the Falkirk Muslim Community Club with 40 attendees. CSREC estimates that through holding dementia awareness-raising sessions and attending various information stalls at community events, it has reached approximately 8,500 people within the Forth Valley.

The awareness-raising sessions have been very well received and had success in clearing misconceptions and widening understanding of dementia within minority ethnic communities. In 2019, CSREC visited the Pakistani Women's Group in Stirling twice. One regular attendee at the group stated, "before CSREC's session, I thought that dementia was simply something that you get in old age and that there was nothing you could do about it...in our culture we just accept it and care for them at home". Another attendee stated that the sessions were easy to understand as the CSREC project worker "understood our culture and our religion".

Figure 2.8 provides a list of the community organisations and cultural events that CSREC has engaged with to provide dementia awareness-raising activities, along with estimated number of attendees.

Figure 2.8: Organisations and events attended to deliver awareness-raising activities

Dementia Advisory Group

CSREC successfully formed its own Dementia Advisory Group, with specialist members including medical practitioners, council officials and social workers, to provide the project with advice based on their own experience and knowledge of dementia in minority ethnic communities. The group held its first meeting on 1 April 2019, and continues to meet each quarter to discuss new initiatives.

Resource sharing

CSREC has undertaken activities to record and categorise the specific barriers and challenges faced by minority ethnic communities in accessing dementia support services. The project worker began compiling a list of barriers at the start of the project and has continued to add to this list throughout the funding period. This list was shared during a learning and sharing workshop with the three other projects in September 2019 for discussion and to gain input. This expanded list of barriers, which included issues identified by all four projects, then became the basis of the barriers and challenges diagram found in Figure 3.1.

CSREC has built strong relations with various organisations, key stakeholders, and service providers throughout the public and third sectors (Figure 2.9). These relationships have allowed CSREC to build a detailed picture of the support available to people living with dementia in the area it covers, as well as gauge the availability of support for people from minority ethnic communities. CSREC has found that although there is no shortage of willingness from these organisations to support minority ethnic communities, they are unsure of how to engage with these communities and uncertain as to the type of support required. To remedy this, CSREC has kept service providers informed of the learning from its project.

Figure 2.9: CSREC Partners

 CSREC Partner Organisations	
<ul style="list-style-type: none"> • Alzheimer Scotland • Age Scotland • About Dementia • University of Stirling Dementia Services Development Centre • Our Connected Neighbourhoods (OCN) • Scottish Health Council • Joint Dementia Initiative – Falkirk • Falkirk & Clackmannanshire Carers Centre • Stirling Carers Centre • Coalition of Carers • MECOPP • Dementia Friendly – Stirling • Dementia Friendly – Clackmannanshire • Scottish Dementia Working Group • Clackmannanshire Third Sector Interface – Health Forum 	<ul style="list-style-type: none"> • Clackmannanshire Social Workers Team • Clackmannanshire Stroke Support Group • Forth Valley Royal Hospital (Dementia Wards) • NHS Forth Valley Equality and Diversity Team • NHS Community Mental Health Team (Falkirk & Stirling) • Faith in Older People • Town Break Stirling • Church Of Scotland Stirling • Article 12 • Re-engage (Formerly: Contact the Elderly) • Soul Space • Dementia Carers Forth Valley • TIDE Carers Network • Stirling Multicultural Partnership

Challenges

The project has had to adopt a very flexible approach to engaging with minority ethnic communities, as many of these communities are dispersed and the understanding of dementia is at such an early stage that most individuals were reluctant to engage with the project. Instead, the project worker has attended numerous community events across Falkirk, Stirling and Clackmannanshire, at places and venues where people from minority ethnic communities gathered in order to maximise opportunities to raise awareness of dementia and inform people about the project. For these reasons, and because of the awareness-raising focus of the project, CSREC has had less direct engagement with people living with dementia. Over the course of the funding period, three people living with dementia and seven unpaid carers have been involved in the project.

CSREC has faced similar challenges to other projects in trying to reverse the deeply entrenched stigma attached to dementia within minority ethnic communities. When conducting initial research for the project application, CSREC found many individuals that were willing to speak about people living with dementia and identifying unpaid carers. However, once the project formally commenced, these individuals became reluctant to engage. CSREC noted that the people who initially expressed interest in the project were only willing to speak about dementia on a theoretical level, and had no interest in discussion which may lead to self-identification of them or their families as living with dementia. CSREC acknowledged that the task of clearing up misconceptions around dementia will be a much longer process than anticipated and will require determination and persistent engagement with different cultural groups.

Summary

The CSREC project ends in December 2020, after delivering a series of awareness-raising activities throughout the central region. CSREC has continued to look into funding from Alzheimer's Research UK and other grant providers to further develop their awareness-raising activity. CSREC has produced a Dementia and Care Information Booklet, which aims to provide comprehensive information for anyone living with dementia. This document has been reviewed by service users and partners and will be translated into relevant languages. The English version is available [here](#). CSREC is also exploring opportunities to develop a stronger presence in Alloa and is working in partnership with another charity to facilitate this.

REACH: Community Health Project

Local context and the approach to the service

The REACH Community Health Project (initially the REACH Healthy Living Project) was established in 2000 in Glasgow with a focus on health promotion to encourage better dietary and exercise habits within minority ethnic communities. It delivers a range of services including mental health and wellbeing; healthy living; and employability. The project's primary aims are:

- to assist people from minority ethnic communities living with dementia to have increased knowledge of their access to the right care and support;
- to empower people from minority ethnic communities living with dementia, resulting in their increased ability to live independent lives for as long as possible; and

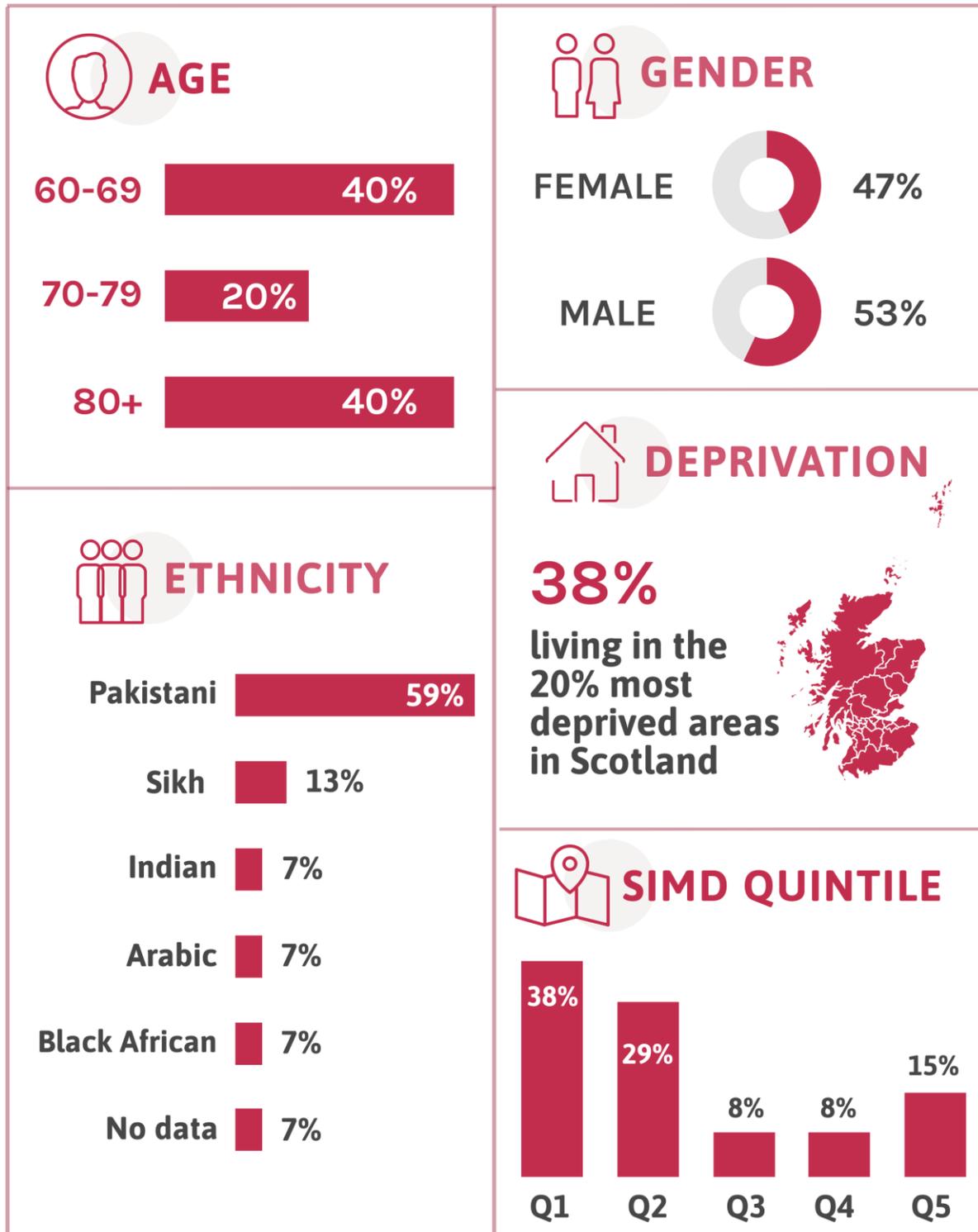
- to reduce the prevalence of the myths and misconceptions surrounding dementia and begin to change attitudes that negatively impact on people living with dementia, their families and unpaid carers.

Implementation of the project

The project's target group was individuals from South Asian Communities living with dementia in south Glasgow, primarily people from the Pakistani, Indian and Bangladeshi communities. REACH targeted these communities, as they believed that they were the most disadvantaged within minority ethnic communities. Disadvantage was based on measures including income and education; the size of the population in the Glasgow area; and the potential for greater vascular type dementias in this group. The project supported 21 individuals and their families.

Figure 2.10 provides a breakdown of service users' age, SIMD quintile and languages spoken.

Figure 2.10: REACH service user profile data



Services delivered

Dementia Link Worker

One of the project's primary service offerings was based around employing a part-time Dementia Link Worker to support South Asian families affected by dementia, and an expectation for the worker to provide six to eight families each with up to two hours support per week. Initially, REACH had planned for the Link Worker service to commence at the six-month mark, to allow the project to first focus on awareness-raising. However, within the first six months, the project engaged six families, and the Link Worker was employed to provide home visits and phone support. The Link Worker acted as the first point of contact for new referrals, and continued to provide home visits and telephone support to service users throughout the project's funding period. They also played a core role in encouraging new service users to attend the Ethnic Minority Dementia Friendly Group established by REACH.

Ethnic Minority Dementia Friendly Group

Another core service established by the project was the Ethnic Minority Dementia Friendly Group (EMDFG), which met fortnightly in a rented room at Govanhill Neighbourhood Centre where REACH has its office. Referrals to the EMDFG were primarily facilitated by the REACH Link Worker, as well as through the strong links that REACH has with two medical practices in Glasgow. LCT funding allowed REACH to cover transport costs for service users and their families to attend this service. People living with dementia who attended the EMDFG gave positive feedback about the support provided and excursions arranged by the group. They valued the opportunity to spend time with people from their own community, speaking their language, to be part of stimulating

activities and to have a reason to get out of the house and enjoy themselves.

“It’s good, I enjoy it. I am very happy to get out of the house...I used to go to other groups, but my health getting worse makes it difficult” (*Service user*)

The EMDFG planned social activities for attendees, such as gardening, board game sessions and Bollywood movie events to encourage service users to shift their focus away from their diagnosis and focus on positive activity. The group also acted as an outlet for family members of people living with dementia to share their concerns with other individuals from their culture, who spoke the same language, and who were experiencing similar circumstances. One attendee living with dementia stated that she is nearly housebound but she felt much better attending the group, and that the group allowed her husband (whose dementia is more advanced) to “dance and talk to other people”. She stated that she appreciated that there were people in the EMDFG who spoke their language that she could talk freely to and who understood what she was experiencing.

Awareness-raising

Through a partnership with Alzheimer Scotland, the REACH project also offered Carers Information Courses targeted at people from South Asian communities. These courses ran for four sessions and covered topics such as memory; understanding dementia; communication; behaviour; meaningful activities; and services and supports. The project delivered three such courses.

The REACH project also offered Dementia Information Participative Workshops, delivered through the partnership with Alzheimer Scotland, locally aimed at the general South Asian community, i.e. individuals and families not specifically affected by dementia. Three workshops were delivered over the course of the funding period, each attended by 15–20 participants.

In addition, REACH built a specialist dementia services database for people from South Asian communities which will be similar to the database which REACH has developed around mental health services.

Challenges

The biggest challenge faced by REACH was the widespread misconceptions and stigma that surrounded dementia amongst the minority ethnic communities that the project supported. They found that several service users and their families had never heard of dementia, and many had misunderstandings of what symptoms were indicative of the disease.

REACH staff reported that there remains a significant amount of stigma amongst the minority ethnic communities supported by the project, with many families in denial or reluctant to admit that their family member may have dementia. This created difficulties for REACH Link Workers in establishing connections and gaining the trust of some referred individuals.

Many individuals and their families initially refused REACH services or allow home visits, with some instead characterising their family member's symptoms as punishment for past misdemeanours.

Some families from the Pakistani and Punjabi communities also believed that the cognitive decline experienced by their family member was simply a normal part of the aging process, and that they did not require any sort of specific support.

As minority ethnic communities in Glasgow are close-knit, REACH also faced difficulties in convincing service users to access other health or support services. Some service users and their families felt that the more people that were aware of their circumstances, the higher the risk that this would lead to information spreading around their community and causing embarrassment for the family.

REACH experienced a major challenge in identifying unpaid carers from South Asian communities for the Carer Information Courses. As a result, only three of the four planned Carer Information Courses were delivered. Within the Carer Information Courses themselves the delivery had to allow for translation into more than one minority ethnic language. Furthermore, REACH staff reported that the resources for unpaid carers that they gathered from mainstream services as part of the family support package, were not culturally appropriate as they used heavy jargon. The language used meant very little to the minority ethnic communities that REACH worked with, and project staff had to invest a significant amount of time during sessions simplifying language to assist unpaid carers to understand.

Similar to MECOPP, REACH experienced great difficulties in recruiting volunteers from target minority ethnic communities. REACH had some engagement with students through launch days and distributing flyers at various locations within the community.

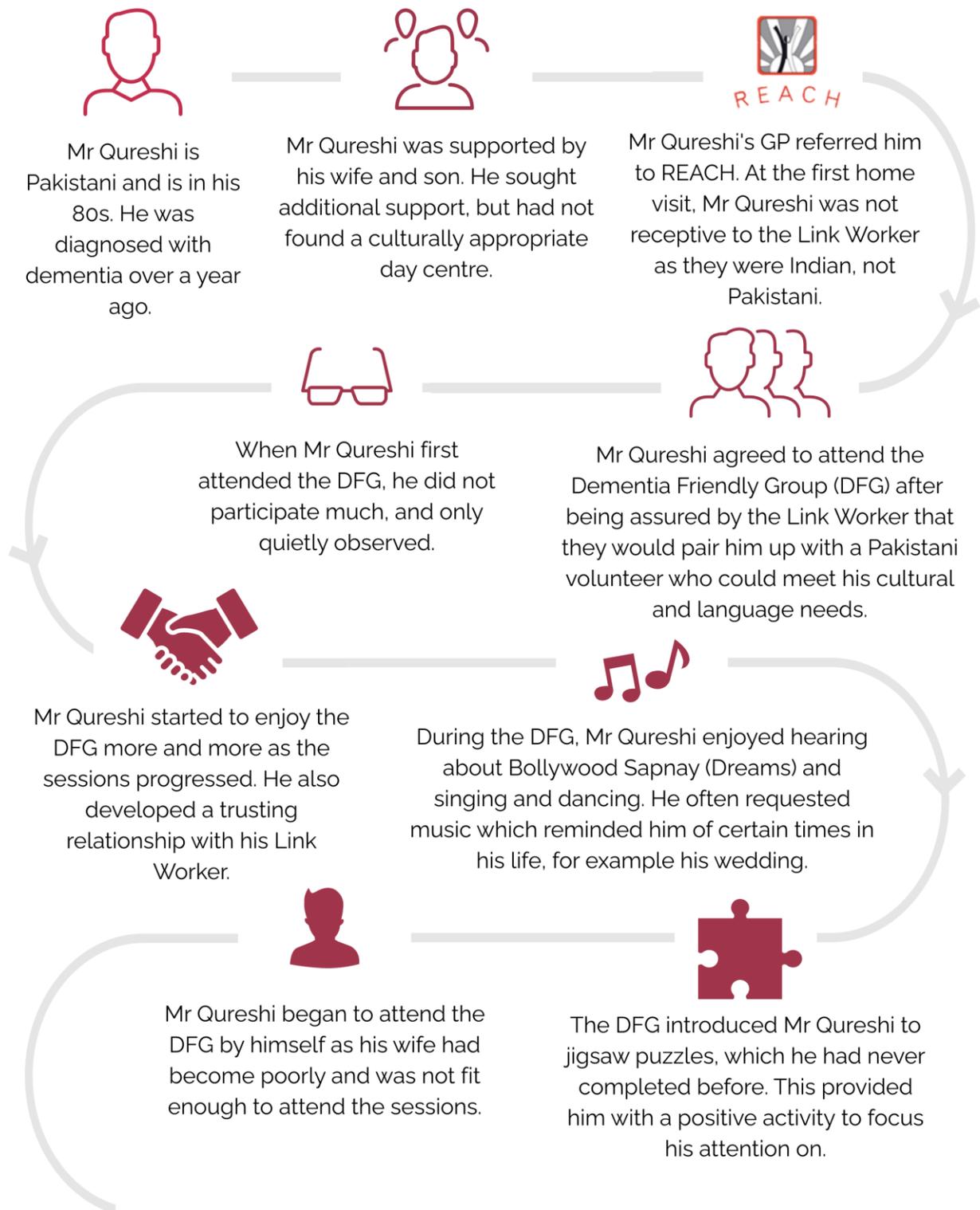
However, when volunteers first attended sessions, some service users felt uncomfortable with male and female volunteers both being in the same group, and this created barriers in their engagement with the activities. Finding language-specific volunteers was also a significant challenge. In addition to individuals from a South Asian community, the EMDFG received attendees from the Chinese and Arabic communities. REACH staff tried their best to cater to these individuals, however, they experienced great difficulties in sourcing Chinese- and Arabic-speaking volunteers.

As awareness of the project increased, this led to enquiries from outwith the target South Asian population, e.g. Roma, Caribbean and African Communities, however, REACH was not able to accommodate them, as the project did not have the resources to meet this demand.

Case studies

REACH compiled two detailed case studies of two service users, detailing their dementia journey and the support they received from REACH. These are presented in Figures 2.11 and 2.12.

Figure 2.11: Case study 1 – Mr Qureshi



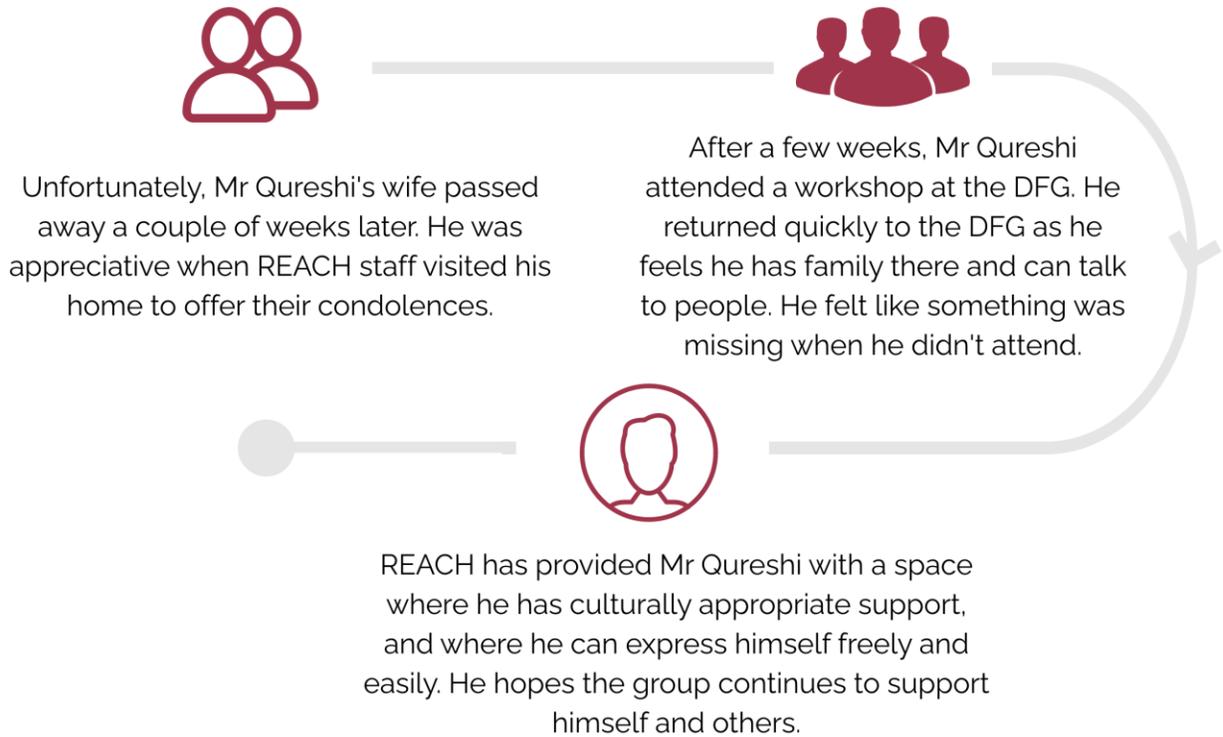
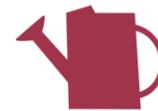


Figure 2.12: Case study 2 – Mr and Mrs Shah





Mrs Shah was very pleased with the outcome, and was relieved that she could speak to someone that understood their situation in Urdu. They became regular attendees at the group and asked their daughter to volunteer at the project.



Mr Shah became more confident in getting outside the house and engaging with other people as a result of attending the DFG. He was particularly interested in participating in the gardening project.



Mr & Mrs Shah are grateful for the the support from REACH. They had never heard of dementia previously, and REACH were able to support them in accessing clear information in Urdu.

Summary

The project officially ended in October 2019 but was given some continuation funding from the 1st March 2020 to the 31st October 2020 to enable them to continue operating until they found a more sustainable funding solution. The DFG continues to meet virtually and training for carers is still available.

3. Summary of outcomes delivered and recommendations

Introduction

Each of the four projects has been successful in raising awareness of dementia amongst minority ethnic communities, providing various types of support to people from minority ethnic communities living with dementia, and providing support to unpaid carers. However, in delivering their services, the projects have illuminated the racial inequality that still prevails when accessing health and social care and how it significantly hinders the ability of families from minority ethnic communities affected by dementia to access critical support.

The four projects were in unanimous agreement that in order to bridge the wide gap between ethnic minority communities and mainstream dementia support services, investment in wider awareness-raising amongst communities about dementia and services available and amongst decision makers and providers about delivering culturally appropriate and accessible services must occur. Although LCT funding has ended, or will soon end, all four projects remain dedicated to continuing their service offerings, expanding awareness of dementia within minority ethnic communities across Scotland, and improving quality of life for minority ethnic families affected by dementia.

Progress against project outcomes

In considering the overall project outcomes for the Minority Ethnic Communities and Dementia programme, each of the four projects have made significant progress towards meeting outcomes identified by the Trust.

Increased number of culturally relevant services in Scotland

All four projects have worked, through awareness-raising or actual delivery of support, to increase the number of culturally relevant services in their respective areas to support people from minority ethnic communities affected by dementia.

ACVO created a toolkit for practitioners to assist them in engaging with people from minority ethnic communities. The toolkit provides information on how dementia services could be tailored to more effectively support people from European ethnic minority communities and includes a checklist to measure effectiveness of engagement. This resource could be adapted to support the needs of other minority ethnic communities.

Demand for MECOPP's Dementia Support Worker continues to rise and MECOPP is continuing to lobby for local dementia organisations, such as dementia cafes and befriending services, to widen and tailor their services to better meet the needs of the Chinese and other minority ethnic communities. MECOPP is also in the early stages of exploring a Cantonese-speaking volunteer group to provide befriending and language support services.

CSREC built strong relationships with dementia support services throughout central Scotland, liaising with them regularly to share information on how to tailor services to reduce access barriers for people from minority ethnic communities living with dementia.

REACH's Link Worker successfully provided intensive support to South Asian families affected by dementia through home visits and telephone support. This was very popular and REACH received requests for this service from individuals from other minority ethnic communities.

Increased engagement with people affected by dementia from minority ethnic communities

MECOPP, REACH and CSREC's projects have been successful in engaging with people living with dementia and unpaid carers. REACH supported 21 individuals living with dementia and MECOPP is providing intensive support to five people living with dementia, and one person going through the diagnostic process. CSREC was also able to engage with three people living with dementia, and seven unpaid carers. Although these are relatively small numbers, the impact of providing support to those individuals and their families is significant and has improved the lives of those affected by dementia.

In setting up the EMDFG, REACH successfully created a comfortable space for people living with dementia and their families to receive culturally appropriate support, engage in culturally relevant activities, and interact with each other, as well as allowing unpaid carers to access a support network.

CSREC made dedicated efforts to engage with community organisations and attended several events to raise awareness of dementia. This provided opportunities for CSREC to engage directly with a small number of people living with dementia and unpaid carers to provide them with guidance and signpost them to access appropriate local support services.

A change in perceptions of dementia within minority ethnic communities

All four projects have delivered awareness-raising activities to change perceptions of dementia throughout their respective minority ethnic communities and local areas.

These awareness-raising activities focused on correcting common misconceptions around dementia, describing symptoms, explaining how dementia affects the aging process, and the types of support that are available and appropriate for people from minority ethnic communities. Drawing all this material together and sharing it more widely as an output of this evaluation will be valuable in helping to change these perceptions.

ACVO worked to change perceptions through launching its toolkit for minority ethnic communities, which provides an overview of common misconceptions of dementia and how differing cultural beliefs may affect each community's understanding of dementia.

CSREC engaged a significant number of people through their awareness-raising sessions, attendance at cultural events, information booths, and distribution of information booklets. CSREC is also developing a toolkit containing information about dementia and the project, which is undergoing review and will be translated into different languages.

MECOPP has delivered various awareness-raising sessions to the Cantonese community in Lothian. The sessions contained information including the various names for dementia across different Chinese territories, how to recognise symptoms, common misconceptions, and details of support services in Lothian.

Deeper learning about the needs of people from minority ethnic communities living with dementia and unpaid carers

Each of the four projects documented the challenges and barriers that they have faced.

Some of the common challenges include misconceptions about dementia, stigma and shame, language barriers, delayed diagnosis, lack of support for unpaid carers, as well as cultural and religious insensitivity in care. All projects detailed these challenges and other learning in their bi-annual reports submitted to the Trust.

CSREC, in recording and categorising the specific barriers and challenges faced by minority ethnic communities, created a comprehensive list throughout their funding period. CSREC periodically shared this learning with their partner organisations to assist them in tailoring their support services to be more accessible for people from minority ethnic communities living with dementia.

In September 2019, the four projects came together for a learning and sharing workshop to discuss the challenges that minority ethnic communities faced and to share strategies to overcome these challenges. Figure 3.1 captures these challenges and barriers across the dementia care and support pathway and this could be a useful visual aid for communicating the needs that must be addressed to support people from minority ethnic communities living with dementia and unpaid carers.

Recommendations

Based on the projects' progress against outcomes and the lessons learnt from delivering their work, we have identified some recommendations which build upon each other, and that could help to inform current and future delivery of support services for people from minority ethnic communities living with dementia.

Recommendation 1 – The projects, and other representatives within minority ethnic communities, should continue to work to improve understanding and awareness of dementia and the services available

The projects have established widespread, noticeable presence in their respective localities and there is an opportunity to build on the work of the projects so that awareness and understanding of dementia amongst minority ethnic communities extends further and more communities are supported to assist decision makers and providers to address barriers to services. The materials created by the projects and the learning from this report should be shared more widely to assist understanding amongst communities and service providers.

Recommendation 2: Service providers should build meaningful partnerships with minority ethnic communities, and organisations that work with them, to better understand their local communities and work together to design appropriate services

If engagement mechanisms are established with minority ethnic community groups and representatives, they could provide opportunities to build trust with the communities and work together to learn about the challenges, test out solutions, and consider the best way to provide more relevant and appropriate services for people affected by dementia from minority ethnic communities.

Recommendation 3: Diagnosis services and care providers should improve the cultural competency of staff and volunteers so that the services they provide to minority ethnic individuals living with dementia are culturally sensitive and appropriate

All four projects identified that the most notable challenge was the lack of cultural appropriateness and understanding within mainstream services, which prevented access for many people living with dementia from minority ethnic communities. Across the projects, toolkits and awareness raising materials were created for providers. This, together with closer working with people affected by dementia from minority ethnic communities and access to relevant learning materials, will support providers to make the necessary changes.

Recommendation 4: As part of the development of local dementia strategies, Integration Authorities should acknowledge and address the needs of people affected by dementia from minority ethnic communities when identifying and designing services and priorities for their local population

Although some of the barriers to dementia services overlap with those faced by the general population, they are heightened, more complex and more prolific for people from minority ethnic communities living with dementia and unpaid carers. Language barriers, misperceptions, inaccurate translations, and lack of cultural awareness prevents access to services. Key decision makers developing local responses to dementia services and care could improve access and the experience of services for people affected by dementia from minority ethnic communities.

Figure 3.1: Barriers and challenges for minority ethnic individuals, families, and unpaid carers to accessing dementia services



AWARENESS OF DEMENTIA

Lack of understanding of dementia across all communities

No equivalent translation of dementia in many languages but can be referred to as “madness” or “crazy” illness

Sometimes not recognised as an illness that requires medical treatment

Lack of awareness of services available

Lack of knowledge of dementia symptoms and risk factors



PRE-DIAGNOSIS

Lack of trust in the Scottish health service - people might go to their home country for diagnosis/support

Lack of awareness that progression of dementia can be prevented/delayed

A perception that there is no point visiting GP about dementia because it is not curable

People don't want to waste the GP's time

People feel they are asking for too much from health services

Reluctance to speak to someone external to their community about their symptoms

Family members may try to hide their parents' illness from others within the community

Lack of understanding and recognition of the early signs of the onset of dementia

Lack of priority - dementia is not seen as an issue that needs medical attention

Interpreters' interpretation of what GP said can lead to misunderstanding

Lack of knowledge of system and where to go for support



DIAGNOSIS

GP and hospital settings can rarely provide language assistance to individuals attending appointments

Diagnosis methods rely on fluency in English e.g. spelling tests in English

Interpreters only interpret, they do not explain and may not be culturally competent

People may be diagnosed with one form of dementia without discussing another form then or later

GP appointments in Scotland might be shorter than in some people's home countries so delivery of diagnosis might be seen as insensitive/rude

Ethnic minority communities groups more likely to have other health issues that could mask or delay diagnosis

People could be put off seeking diagnosis if another member of their community had a negative experience



CARE AND TREATMENT

Individuals can be uncomfortable to receive care or treatment from someone outwith their community

Families may consider residential care/external carers as unacceptable options

Many facilities are not sensitive to gender-specific requirements, e.g. having a person from the opposite gender assist with personal hygiene

Lack of dementia specific training for care providers

Family carers lack skills, knowledge, training to care for people living with dementia e.g. moving/ handling and it is difficult to access training due to lack of interpreter support

Support/health services might not be culturally competent

Unpaid carers do not always identify themselves as a carer

Lack of awareness of services



POST-DIAGNOSTIC SUPPORT

People living with dementia can revert back to their first language, and as a result their English ability diminishes, which restricts their ability to access services

Most dementia support services are geared towards the English-speaking majority

Dementia support services rarely have multi-lingual staff who can offer support in other languages

Benefit and assistance application processes generally require a good command of English to complete forms

Lack of knowledge of support available