Evaluation of the Age UK Dementia Maintenance Cognitive Stimulation Therapy (MCST) Programme

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Prepared for: Age UK

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Contents

1: Acknowledgements

AUTHORS

The report was written by Danica Minic (Research Director) at Research Works Ltd who led the MCST evaluation and was supported by Gemma Haddock (Research Director) and Jill Barnett (Field Manager). Research Works Ltd are a research consultancy which specialises in delivering social and market research and evaluations for public and third sector organisations.

2: Introduction

2.1: PROJECT CONTEXT: MCST PROGRAMME

Cognitive Stimulation Therapy (CST) is the only non-drug treatment recommended by the National Institute for Health and Care Excellence (NICE) to improve cognition, independence and wellbeing in people living with dementia. When someone is diagnosed with dementia, they may be offered a course of CST, which usually runs for a set period of 7-14 weeks and offers a programme of themed activities. However, once a course of CST finishes, there is often limited, or in some parts of the country, no provision of services to support people living with mild to moderate dementia, as well as their families and carers, on an ongoing basis.

Longer term, Maintenance Cognitive Stimulation Therapy (MCST) was developed to maintain the positive benefits of CST through themed and structured activities. MCST is based on the same principles as CST and aims to actively stimulate and engage people living with mild to moderate dementia (including all diagnosed types with or without a formal diagnosis) and mild cognitive impairment, in a learning and social environment. Activities can include things such as word games, physical activity, arts and crafts and group discussions.

Given the potential benefits that MCST can bring to people living with dementia, and their families and carers, Age UK was keen to grow and expand MCST based services across the Network, and to develop a consistent and high-quality approach to delivering such services.

With generous funding from the Association of British Insurers' (ABI) *'Covid-19 Support Fund'*, which launched in May 2020 to help those hit hardest by the Coronavirus pandemic, Age UK have been able to do that by setting up 157 new MCST groups across the Age UK network established as part of the Grant Programme (also referred to as the "Programme").

As the programme started during the Covid-19 pandemic, Age UK set out to provide both virtual and face-to-face MCST service. Network Partners participating in the programme were free to decide whether to deliver virtual or in-person MCST, or a mix of the two. Over the course of the programme, the majority of MCST groups were delivered face-to-face (133), whereas 24 were delivered online. Out of those 24 online MCST groups, 10 were delivered by Age UK National Telephone Friendship Service (TFS). TFS joined the MCST programme in late 2022 to boost the online MCST provision and offer this form of support to people who cannot access it in person. 1061 clients took part in the MCST programme over three cohorts of service delivery: October 2021 – April 2022 (cohort 1); April 2022 to January 2023 (cohort 2) and January to September 2023 (cohort 3).

The aims of the Programme were to:

1. Improve wellbeing and cognitive abilities for people living with mild to moderate dementia (with or without a formal diagnosis) through greater access to MCST-based interventions.
2. Improve wellbeing for carers of people living with mild to moderate dementia through respite and peer support provided by greater access to MCST-based interventions.
3. Improve knowledge, skills, and confidence in delivering MCST-based intervention/s for staff and volunteers.

2.2: EVALUATION OBJECTIVES

Age UK commissioned this evaluation to understand the extent to which the MCST programme achieved its intended outcomes and to enable learning from early cohorts to be shared over the duration of the programme. In addition, the evaluation had two other major objectives:

- To compare the effectiveness of face-to-face and online MCST;
- To understand how the delivery of Age UK's MCST programme differs from existing provision of support for older people living with dementia.

The evaluation objectives are presented in more detail below:

Theme 1: To compare the effectiveness of delivering MCST virtually vs. face-to-face across the key outcomes:	
Outcome 1:	**Evaluation questions**
Improved wellbeing and cognitive abilities for people living with mild to moderate dementia through participating in MCST activities.	• How do face-to-face and online MCST interventions compare in terms of their **impact** on people living with mild to moderate dementia? º In terms of achieving improved cognitive abilities, wellbeing and quality of life? • How do face-to-face and remote online MCST interventions compare in terms of the **practicalities** involved in running group sessions: º Identifying people suitable for the interventions delievered in these ways; º Securing adequate delivery mechanisms and environments; º Challenges and success involved in each of these delivery methods.
Outcome 2:	**Evaluation questions**
Improved wellbeing of carers of people living with mild to moderate dementia through respite and peer support enabled by greater access to MCST interventions.	• How do face-to-face and remote online MCST interventions compare in terms of their impact on carers of people living with mild to moderate dementia? º In terms of achieving improved wellbeign, quality of life and mood?
Outcome 3:	**Evaluation questions**
Improved knowledge, skills and confidence in delivering MCST interventions to people living with mild to moderate dementia.	• How effective was the training in preparing partners to deliver MCST interventions? º In terms of their knowledge, skills and confidence? • What were key challenges and successes involved in the delivery of MCST interventions? • What worked well and less well in delivering the programme?
Theme 2: To understand how the delivery of Age UK's MCST programme differs from existing provision of support for older people living with dementia.	

Table 1: Evaluation objectives

2.3: EVALUATION METHODOLOGY

The evaluation used mixed methods to capture data about client, carer and staff experiences of the programme, as well as its impact and outcomes. The research involved the following research methods:

Quantitative research: Analysing assessment data	Qualitative research: Interviews and group discussions	Desk research and expert interviews
MCST programme clients • SMMSE and QOL-AD assessments completed **at start of programme and after the 24th session.** **Carers** • QOL-AD and C-DEMQOL questionnaire completed by carer **at start of programme and after the 24th session.**	**Clients and Carers** • 56 x pair and 13 x single depth interviews with clients and their carers (where appropriate) to explore their views on the sessions and the impact they have. • 46 follow-up individual interviews with clients and their carers. **Age UK staff** • 19 x pair or individual depth interviews. • 13 x focus group discussions.	**Assessment measures review** • Review of measures used to assess cognitive capacity and quality of life in older people living with dementia. **Dementia support review** • Review of how MCST fits in the broader landscape of dementia support. • 6 x expert interviews. **Partner information and data** • Analysis of information provided by partners on monitoring forms to unpick challenges and successes.

Table 2: Evaluation methodology

Quantitative data

The following measures were used to assess the impact of the programme on clients and carers:

- The Standardised Mini-Mental State Examination (SMMSE) – a screening test of cognitive function in older people;
- Quality of Life in Alzheimer's Disease (QOL-AD) – a questionnaire designed to assess quality of life in people living with dementia, both from their perspective and the carer's point of view;
- C-DEMQOL – a questionnaire used to measure quality of life of carers supporting people living with dementia.

The measures above were selected after a review of a range of potential measures to be used in the evaluation.[1] These measures were chosen as most suitable based on the following criteria: being very established and widely used with older people living with dementia and their carers; being suitable for assessing people living with mild to moderate dementia; and being practical for Age UK staff to administer in terms of their complexity and time required.

Network Partners delivering the MCST programme engaged clients and carers to complete the questionnaires at the start (within two weeks after starting) and end of the programme (i.e. at 24 weeks of the programme). Staff completed SMMSE and QOL-AD questionnaires with clients, whereas most carer questionnaires were self-completed. Staff then shared anonymised questionnaire data with the evaluation team for data processing and analysis, as well as demographic data of clients.

Excel data tables were produced for analysis to compare baseline and final scores for cognitive function and quality of life in clients, as well as carers' quality of life. Data analysis explored the extent to which clients' cognitive function and quality of life and carers' quality of life remained stable, declined or improved over the duration of the programme. In addition, it examined whether these changes over time varied across different groups of clients, based on gender, age, type of dementia, and other relevant demographic and contextual characteristics.

Quantitative data was collected from 397 clients and 209 carers, although the sample for individual questionnaires used varied, as follows: the SMMSE assessment was completed by 349 clients; QOL-AD (client version) by 377 clients; QOL-AD (carer version) was completed by 209 carers; and C-DEMQOL by 179 carers. A more detailed sample breakdown is provided in Appendix 1.

This sample size allowed for analysis to be broken down by different demographic criteria to explore any differences between groups of clients. However, this was not possible in all cases. For example, the sub-sample for ethnic minority groups was too small to allow for analysis of any differences based on ethnicity. These and other strengths and limitations of the data and methodology more generally are discussed in the final section of this chapter.

Qualitative research with clients, carers and staff

Qualitative research adopted a staged approach to capture data at different points of the programme and enable researchers to follow-up a proportion of clients and their experiences over a period of time:

- Half of the clients were interviewed midway through the programme after 3 months and the other half at the end of the programme. This ensured the research could capture clients' views of the programme at different points of their experience.
- Clients and carers interviewed at 3 months were then also followed-up with another, shorter interview at 6 months to track any changes in their experience over time.

Different qualitative methods were used to collect the data as follows:

- **Paired depth interviews with clients and carers:** Depth interviews were chosen as the most suitable method to give respondents more time and allow the moderator to adapt to the needs of individual respondents. In addition, initial interviews were conducted with pairs of clients and carers, where possible, in order to:
- ° Help older people living with dementia feel more comfortable as they can be supported by a relative (carer) or a close friend;
- ° Allow carers to share their observations about the impact of the programme or a service on clients.
- ° Explore the impact of the MCST interventions on carers too.

The interviews were 45 minutes long and involved a mix of face-to-face and remote methods.

- **Follow-up interviews with clients:** A proportion of clients were followed-up three months later with shorter, telephone or online interviews to help us understand any fluctuations and changes in their engagement with the programme and the impact it is having over time. These follow-up interviews were 20-25 minute long.
- **Follow-up interviews with carers:** Separate, follow-up interviews were conducted with carers to allow more privacy for them to share their thoughts on the impact of the programme on them. These interviews were carried out online or via the phone and were 20-30 minutes long.
- **Depth interviews and group discussions with Age UK staff:** A mix of depth interviews and group discussions was used to conduct research with staff delivering the MCST programme. Depth interviews were used to help understand different experiences by different delivery partners, whereas group discussions allowed staff to share and exchange their experiences, views and learnings. Depth interviews were 45 and group discussions 90 minutes long and were conducted remotely, using Zoom or Teams.

The following sample of clients, carers and staff was included in the evaluation:

MCST clients	Carers of MCST clients	Age UK MCST staff
67 clients **A mix of:** - Those who attended face-to-face and online MCST. - Different types and stages of dementia (ranging from mild cognitive impairment to moderate dementia). - Different demographic groups. - Different geographic areas across Age UK partners.	**58 carers** - Predominatly partners or adult children of clients, although a small number were siblings or friends.	**75 staff members from 49 local Age UKs**

Table 3: Qualitative sample

While the client sample was recruited to be diverse as above, it also reflected the overall profile of clients so was biased towards certain groups. The client profile and the sample were balanced in terms of gender, but they were skewed towards those who attended face-to-face, were over 75 years old, and were White British. A detailed qualitative sample breakdown is provided in Appendix 1.

Desk research and expert interviews

Desk research was conducted to review potential assessment measures to be used in the evaluation. Once the measures were chosen, further desk research was carried out to review how they were used in other studies with people living with dementia and how their results were interpreted.

Desk research also helped inform qualitative research. Firstly, Network Partners' monitoring data provided early insight into challenges and successes experienced in the programme, which helped identify additional questions for the discussion guides. Secondly, a review of literature on MCST and other dementia support informed the approach to exploring how MCST was different from other dementia support services.

In addition, six expert interviews were conducted to complement data and evidence and understand better how MCST fits within the broader landscape of dementia support services. All six respondents worked in roles where they were directly involved with dementia support services, through commissioning, delivering or researching those services. Respondents were selected to represent a range of perspectives and experiences and included: an academic; a health professional referring patients to dementia support services; two commissioners of dementia support services (one working at the NHS and the other at a local authority), and two Network Partner dementia service co-ordinators.

Strengths and limitations of the evaluation methodology

There are some potential limitations in this study that should be borne in mind when considering the results. Some of these limitations have been addressed through the evaluation design and project delivery, whereas others that could not be addressed were considered in the course of analysis. The section below outlines these issues, as well as the strengths of the evaluation design providing confidence in the results.

Firstly, the evaluation methodology needed to be practical and ethical in the context of the delivery of a dementia support service. This had some impact on how the data was collected:

- It was not practically feasible for the research team to collect the assessment data instead of staff delivering the service.
- It was not practically or ethically feasible to impose selection criteria for participation in the study, for example, to control for the extent of client cognitive impairment at the outset or that there were no other major health or disability factors impacting on their later outcomes.
- The amount of data staff was asked to collect from clients needed to be considered so as to not create too much burden for both staff and clients. As no data was collected on other factors potentially impacting participant outcomes (for example, medication, depression, physical health), it may be difficult to separate the impact of the intervention from the impact of these other factors on client outcomes.
- There were small variations in whether the final assessment data was collected exactly 24 weeks and sessions after the programme started or a couple of weeks earlier or later, depending on the practicalities of individual services. That is, the duration of the period over which clients were followed varied slightly, which could potentially impact on scores of some clients.

Secondly, while the overall quantitative and qualitative samples were robust, some sub-samples were small, meaning that quantitative findings based on those should be treated with caution. For example, as most Network Partners provided face-to-face MCST, the sub-sample for online MCST included 36 clients. At the same time, qualitative research explored experiences of online MCST in depth, so the evaluation was still able to understand experiences and the impact of this mode of delivery. Certain other sub-samples, however, were too small to allow analysis, for example, there were only 11 clients in the quantitative sample who were not White British or White Other. The evaluation therefore cannot report on the impact of the programme on clients from ethnic minority groups and future studies will be needed to address this.

Where possible, some of the methodological challenges above have been addressed through the evaluation design or MCST programme delivery:

- Age UK staff were trained to administer the assessment questionnaires to minimise potential errors and bias that can arise when non-researchers and staff delivering a service are collecting data from clients in the service. All assessment data has also been rigorously checked by the evaluation team to query and correct any errors.

- The mixed methods design allowed the evaluation to triangulate quantitative and qualitative findings, providing more confidence in findings around the impact of the programme. For example, clients, carers and staff all commented on the positive impact of the programme on clients' mood, which was also reflected in the quantitative data (i.e. small improvement in client mean score for mood in QOL-AD).

- Clients and carers were tracked over time to allow researchers to capture their experiences and data on the impact at different points in the programme. Clients and carers were also interviewed both together and separately, ensuring they were able to share any sensitive comments privately.

- Another strength of the study is its robust quantitative and qualitative samples, which ensured that a significant proportion of clients, carers and staff were included in the study. Namely, quantitative data was available for 37.4% of all clients in the MCST programme, and the qualitative research included 200 respondents and captured different perspectives of clients, carers and staff. In addition, the quantitative samples for baseline and final data included exactly the same clients and carers, allowing for more confidence in findings regarding any changes in their scores over time.

3: Process evaluation: what worked well and less well in face-to-face and online MCST

3.1: MCST PROGRAMME SET-UP

3.1.1: CLIENT REFERRAL

Age UK staff interviewed in qualitative research reported using a wide range of referral pathways and promotion channels to recruit clients for their MCST groups:

Referral pathways included:	Promotion channels included:
• **Age UK** groups, services (e.g. day centres, befriending) and databases; • **Health professionals** (e.g. GPs, local dementia teams/memory clinics, mental health teams, neurology specialists, Admiral Nurses, social prescribers, wellbeing/ keeping well services, NHS CST programmes); • **Other dementia groups and services** (e.g. memory cafes, Singing for Brain, Alzheimer's Society, local networks of dementia support organisations); • **Other not-for-profit organisations**, e.g. Red Cross; • **Independent living services and care homes;** • **Carer organisations.**	• **Age UK** website, social media, shops; • **Community and public services and venues,** e.g. leaflets or visits to libraries; leisure centres, community centres, churches; • **Health services,** e.g. posters at GP surgeries and memory clinics; • **Other dementia, carer and older people charities**, e.g. their communications; • **Carer newsletters;** • **Local newspapers;** • **Door-to-door leaflets.**

Table 4: Referral pathways and promotion channels

"We did some internal marketing via leaflets, posters, flyers and telephone calls to members. We picked up a lot of clients through that process, but we also advertised on Facebook and other social media sites, and the Age UK website. Posters were taken to care homes, hospitals, doctor's surgeries, local charities, churches and network events. We also emailed over 80 social prescribers." - Staff

Some of these referral pathways proved more productive than others. Based on the programme monitoring data, a significant proportion of referrals came from other Age UK services. Family and friends were another major source of referrals, followed by health professionals and other advice agencies, as shown in the chart below:

Referral source

26% — Age UK
21% — Family and friends
12% — Self-referral
14% — Health professionals
14% — Other advice agencies

Legend: ■ Age UK ■ Family and friends □ Self-referral ■ Health professionals □ Other advice agencies
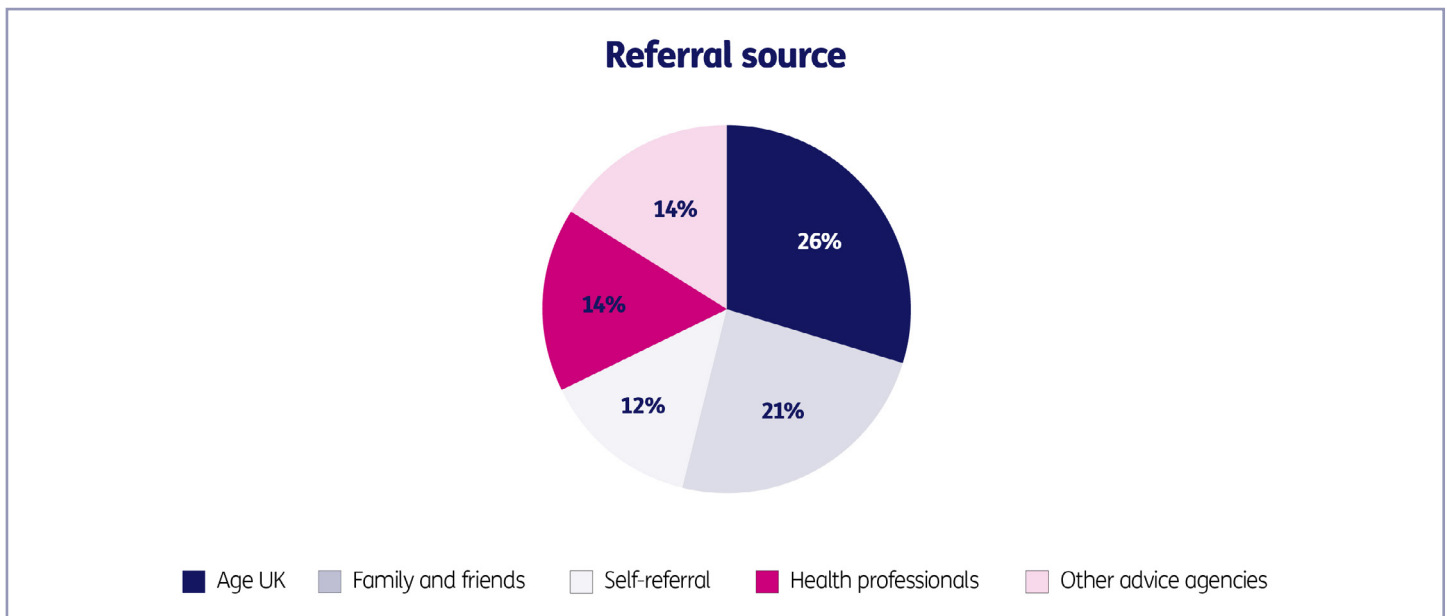
Figure 1: Participant referral sources for the MCST programme

Thinking about these different referral pathways, Age UK staff delivering the MCST programme highlighted the more and less successful pathways in their experience:

- **Other Age UK groups and services:** These were felt to be most productive for recruiting MCST clients.
- **Other dementia support services:** Most partners in all three cohorts also found that getting referrals from other dementia support organisations worked very well. There were rare exceptions to this, for example, a couple of staff reported they received very few, if any, referrals from certain dementia support charities, and wondered whether the reason was that these organisations were reluctant to 'share' their clients.
- **Health services:** Partner experiences were more variable with regards to referrals from health services. Some staff reported they did not receive as many referrals from GPs and other health services as they hoped for. However, others had more productive relationships with health services and received more referrals from GPs, memory clinics, mental health and neurology teams, Admiral Nurses or NHS CST. Some partners particularly highlighted social prescribers within their local Primary Care Networks (PCNs) as a very productive source of quality referrals. In particular, a partner providing online MCST found that social prescribers were interested in referring clients to their service and that the quality of their referrals was higher compared to other referral routes.

Promoting the service through a range of digital and area-based communication channels worked well for most partners. Staff reported that most productive promotion channels included Age UK social media and website, leaflets at local GP surgeries, and local carer newsletters. Some other channels were reported as less successful, for example, one partner thought their door-to-door leaflets resulted in very few referrals.

"Often younger people who had seen adverts online were enquiring for their mum or dad who were the primary carers for their partners." - Staff

Qualitative research with clients and carers further found that carers often pro-actively sought information about dementia support services and activities, e.g. searching for dementia clubs online, or phoning Age UK. Some carers also cited newsletters for carers as a source of information about MCST, which suggests that communications directed at carers may be another productive promotion channel.

Factors affecting client referrals and recruitment

Network Partners reported varied experiences of client referrals as some partners found client recruitment easy and others challenging. For example, a few partners found recruitment challenging due to low awareness of MCST and anxiety some older people living with dementia felt about joining a new group. At the same time, other partners reported they found client referrals straightforward, as they could rely on existing relationships with a wide range of other services for referrals. There were similarities and differences in terms of the factors affecting referrals and recruitment across these different experiences:

- **'Warm contacts':** Many MCST staff found that client referrals worked best where they or their partner organisations had prior contact with potential clients through other services. Generally, those who recruited clients from existing Age UK services found client recruitment easiest. Recruiting through partner organisations, e.g. other dementia services, also helped to provide 'warm contacts' among people living with dementia and their carers who were already accessing services.
- **Stage of dementia:** Some staff highlighted challenges in recruiting people living with mild to moderate dementia, as people in early stages may not identify as having dementia and may not be interested in joining a MCST group. At other times, recruitment took longer because some of the referrals were for people living with advanced dementia, some of whom were assessed not to be suitable for the programme. To judge whether someone may be a potential MCST client quickly and reliably, one Network Partner stressed the importance of speaking to them and their carers directly, rather than sourcing this information from referring organisations.
- **Fear of Covid-19:** Staff delivering MCST during the Covid-19 pandemic found that fear of Covid-19 was another reason that made recruitment to face-to-face MCST more difficult. While fear over Covid-19 subsided throughout 2022 and 2023, a couple of partners whose MCST groups started in the winter of 2023 reported some older people were still concerned about attending in-person activities due to Covid-19.

- **Low social confidence in people living with dementia:** Some clients, carers and staff also commented how clients initially felt apprehensive about attending a new group, as they felt they lost their social confidence. To overcome this initial anxiety, a carer suggested that Age UK should allow for taster MCST sessions, where clients could experience the programme before fully committing. Another carer reported their relative was offered a taster session, which helped them feel reassured as they were initially reluctant to attend.

"I was a bit apprehensive about going to begin with, but once I got stuck into it I thoroughly enjoy every Friday." - Client

"He did not want to go but they offer a (free) trial session and now he goes along every week." - Carer

All clients and carers who took part in the evaluation consented to their anonymised quotes being used in the report. Most have also consented to their anonymised quotes being used for media, fundraising and campaigning purposes by Age UK. However, in a few cases clients or carers did not consent to these additional purposes. If you are a Network Partner wishing to use quotes from this report for these additional purposes, please check with Age UK National which quotes are suitable for this.

- **Client motivations to take part in MCST:** Clients' motivations for joining their MCST programme were a key enabling factor in their recruitment. These motivations varied, but most clients joined their MCST group because they wanted:
  - To keep their mind active, get stimulation, and slow down dementia;
  - To improve specific skills or cognitive functions, e.g. communication, writing, memory;
  - To meet people and socialise;
  - To learn how to cope with dementia.

  In addition, those attending face-to-face sessions appreciated being able to attend an activity outside of their home, having something to do and somewhere safe to go. Carers cited similar reasons for wanting their family members living with dementia to attend MCST groups.

- **Cost:** With the 'cost of living crisis' in 2022-2023, some staff highlighted cost as a barrier to accessing their MCST service. For example, staff commented on having to keep their sessions free or 'low-cost' to attract more interest, or in a few cases, having to lower their initial fee per session. A few staff respondents also pointed out that recruiting clients in less affluent areas was more challenging, as residents were less likely to want to travel to access services or pay for them.

- **Transport:** Poor transport links, cost of transport and unreliable local community transport services were also sometimes mentioned as barriers for older people joining their local MCST face-to-face groups. In addition, clients often depended on their family members being able to take them to their MCST groups, which made attendance more difficult for some.

- **Local dementia support offer:** Some staff also highlighted the impact of the broader landscape of dementia services locally on the level of interest in Age UK's MCST service. In so doing, they painted a picture of highly variable and patchy local dementia support offer, where local provision could either make MCST recruitment easier or more difficult. For example:
  - The Network Partner being the main dementia services provider in their area made the recruitment easier for some;
  - Having free dementia services locally beyond the Network Partners' offer made it more difficult to charge a fee for MCST in some places;
  - Other dementia services tended to include carers, so some potential clients were put off by the idea they should take part in MCST on their own;
  - Having a well-developed network of local dementia support services improved the visibility of Age UK's MCST service and helped recruitment efforts;
  - Low levels of partner organisation and client awareness of what MCST offered that wasn't already provided by other dementia services was seen as another potential factor affecting interest in the MCST service locally.

"It takes a long time to get people on board and understanding what MCST is." - Staff

In addition, the research highlighted some challenges specific to recruiting clients to online MCST, but also reasons why online MCST attracted some older people and helped expand the reach of Age UK MCST services. The following reasons were cited as barriers to engaging with MCST sessions online:

- A lack of familiarity with using digital technology, as well as not having email or digital devices in some cases;
- A perception – shared across many clients, carers and staff – that face-to-face sessions enabled better and more social interaction, as well as opportunities for older people to leave their house;
- Older people's eagerness to re-establish face-to-face contact following the prolonged social isolation during Covid-19 pandemic lockdowns.

"In the face-to-face groups there is more chat, they build friendships, they support each other, they talk about things that they don't talk about at home, they have that interaction outside the home. It is almost like a support group." - Staff

However, most clients, carers and staff also recognised that online MCST allowed a wider range of older people to be recruited and participate in Age UK MCST, for the following reasons:

- **Accessibility:** Some found online sessions more convenient and easier to attend than if they had to leave their house. This included people who were housebound or had other barriers to leaving their house and mixing socially, for example, anxiety. A staff respondent also reported that fewer clients missed their online sessions, as face-to-face sessions were sometimes missed during festive days or due to illness.

"I find it much easier because you're not face to face. It's a really nice group and I do enjoy it; I prefer it; you can say more things when you're not in a room with other people; you don't feel embarrassed." - Client

"Online is better than nothing, it's better to have something rather than not anything at all. It's other people and you're not sitting in on your own; it's really hard for me in the wintertime; Covid was driving me nuts." - Client

- **Convenience:** Some online MCST clients commented these sessions were more convenient to attend so that they personally were more likely to attend them.
- **Alternative where face-to-face is unavailable:** All respondents felt online sessions were extremely helpful where clients were geographically dispersed, lived in an area with no CST/MCST, or if there was another pandemic-induced lockdown. In those situations, online programmes were felt to be very helpful back-ups that worked well and achieved many benefits.

"Travelling could be a problem, it's OK if my son is here with me, but if he's not, then it would be the problem of getting wherever the place is; it's certainly much easier doing it from home." - Client

"Online allows those who would not be able to attend in person to participate - either because of mobility issues, because they'd find it stressful or because they don't have an offer locally." - Staff

3.1.2: CLIENT ASSESSMENT

As explained in the introduction, clients' cognitive abilities and quality of life were assessed at the outset and the end of the MCST programme, using the SMMSE and QOL-AD questionnaires. In addition, carers completed the C-DEMQOL questionnaire which focused on different aspects important for their quality of life as carers of people living with dementia. These assessments were used both for the purposes of the evaluation, but also to understand clients' and carers' situation (QOL-AD and C-DEMQOL) and help gauge someone's suitability for the programme (SMMSE).

Client and carer experiences of assessment

Many clients in our qualitative sample did not remember they were assessed, or if they did, they were unsure what was involved in assessments. Those clients who remembered being assessed, mostly reported positive experiences. They felt relieved the assessments were informal and relaxed, which they thought was very different from their experience of tests in memory clinics which they found stressful.

"There was somebody there who sat with me for some of the time and we chatted about some of it. Nothing was ever uncomfortable. The people that are involved seem to be very pleasant all of them and they are interested. It works quite well." - Client

"It was easy, very well presented, they did a good job of it, made mum feel very comfortable. I only did my bit of what I do with my mother … absolutely fine." - Carer

Only a small number of clients reported feeling uncomfortable about some questions, either because they thought they were intrusive or difficult to understand. At the same time, they appreciated that their answers would provide important information to staff so they can better support them.

Staff comments highlighted the importance of reassuring clients and carers around the assessments. In their experience, clients' response to the assessments greatly varied. While some seemed comfortable to answer all the questions, others found certain questions difficult, so appreciated staff having a relaxed approach. Staff also reported that a few carers felt apprehensive about the potential emotional impact of the questionnaires on their loved ones or how that data would be used, but felt reassured after speaking to staff.

Staff feedback and learnings on using the assessment measures

Staff also gave useful practical feedback on using the questionnaires to assess older people's suitability for MCST and understand their situation:

- **SMMSE:** Many agreed that the SMMSE gave them a basic assessment of someone's suitability for MCST, but stressed this was used in conjunction with their wider judgement of the person. For example, some staff reported they had clients with low SMMSE scores but who engaged and were able to participate and benefit from the sessions.

  Some staff further suggested it was important to consider the timing of SMMSE assessments to ensure optimal conditions. For example, a staff respondent who led a MCST group at a care home found older people performed better in the morning, as they were less alert later in the day, potentially because of medication.

  In addition, staff stressed the importance of training for using the SMMSE questionnaire, as they felt this assessment required more knowledge and familiarisation than others used in the programme. For example, one MCST staff respondent thought that it took staff longer to get used to using the SMMSE questionnaire to assess someone's suitability. Another staff respondent reported they felt embarrassed asking some of the questions, as they worried they may be seen as patronising to some older people living with mild dementia. In this context, a few staff respondents felt they needed more training on how to administer this questionnaire.

"Everyone was happy to sit down and have the conversation, although the carers were sceptical of why and what you were going to ask the clients. Once I explained, they were generally fine – we only had one negative response where the primary carer wasn't happy for me to interview the client on their own, so I asked them not to answer for them, or prompt. But halfway through she just asked me to stop as she said it was cruel because he couldn't answer the questions." - Staff

- **QOL-AD:** On the whole, staff found the QOL-AD questionnaire helpful for identifying areas where clients may struggle and need support, but also highlighted some considerations for administering this questionnaire:
  - ° **Privacy:** Staff sometimes found that clients and carers needed privacy when completing the QOL-AD questionnaire, especially when answering questions about relationships with family members. For this reason, some mentioned it can be difficult to ensure privacy in venues where there is no separate room.
  - ° **Preparation:** Others stressed the importance of having an informal conversation beforehand to introduce the questionnaire, as some older people seemed bemused by being asked a range of personal questions.
  - ° **Confidentiality:** In one instance, a carer had to be reassured that the assessment was confidential, as they thought it may be reported to social services.
  - ° **Time:** A couple of partners found that QOL-AD questionnaires could take a long time because people wanted to talk about their situation, as that was the first opportunity they had to discuss their situation in many cases.
  - ° **Emotional burden:** Some staff explained QOL-AD (and C-DEMQOL) questionnaires were sometimes emotionally demanding for everyone, including staff, as they revealed difficulties clients and carers experienced.

"Make sure you do the carer one separately from the one for the person with dementia, without the carer in the room, because they will try to influence the answers, it's only trying to be helpful but still (an issue)." – Staff

- **C-DEMQOL:** This questionnaire was seen to provide useful information on areas where carers were struggling, so staff could signpost them to relevant support (for example, dementia support information and advice, wellbeing and other workshops for carers, benefits advice) or offer them to set up a carer group for them. Staff also shared some specific experiences of using this questionnaire:
  - ° A few staff respondents reported they had mixed reactions from carers to being asked to complete a questionnaire about their life. While some carers felt pleased staff were interested in their wellbeing too, others appeared confused by this as they expected the focus would be solely on older people living with dementia.
  - ° Some staff also commented that carers appeared very busy so completing evaluation questionnaires was not seen as a priority. In this context, staff felt that giving questionnaires to carers to take away, complete and bring back worked best.

"When we did the first set of questionnaires it was very emotional. The CDEMQOL questionnaire in particular was so emotional that I decided to give them a copy to take home and fill out by themselves. But the first-time round, they answered very easily and fairly, and it gave us chance to talk to the carers and find out their needs. That led us on to run several groups specifically for the carers, in addition to this project, which weren't funded." – Staff

"The people that filled them out, it was enlightening to go through them and see the responses to them, with some of them, based on the answers that came back, I went back to them afterwards and said once our Wayfinders service is up and running, would it be of benefit to you, we can have somebody contact you to support you and they were very open to that." – Staff

Assessment experiences specific to online MCST

In most cases, online MCST clients were still assessed face-to-face, as staff felt this allowed them to get to know the person and understand their situation better. In addition, there was a feeling that administering the SMMSE questionnaire online posed some challenges, as some of the tasks were more difficult to pose and observe online.

A smaller number of Network Partners completed assessments online, as visiting clients was not feasible since they were geographically dispersed. One partner who conducted assessments online described how they adapted the SMMSE questionnaire for online assessment. Firstly, staff created a PowerPoint presentation to help with the virtual delivery of assessments, for example, pictures of objects that needed to be shown. Staff guided clients and/or carers (where present) how to move the camera to show actions or clients' answers (e.g. their drawing or writing) where needed.

"With regards to completing the SMMSE virtually, we used an extremely basic 4 slide PowerPoint in order to show pictures/phrases that needed to be shown. We used it purely in place of cards that might have been held up in person for example. The rest of the assessment was easily done via video chat as it could be carried out in much the same was as if it had been face-to-face." - Staff

In another case where assessments were conducted online, staff felt that certain questions were too challenging to complete online. They therefore decided to omit those questions and then follow the SMMSE guidelines for calculating an adjusted total score in situations where questions were missing.

Two further issues were raised in terms of the impact of conducting assessments online. One respondent felt that clients could sometimes find it challenging completing the assessments in an unfamiliar environment (i.e. online). Another staff respondent thought that it was more difficult to provide emotional support to clients where they needed it, following disclosure of challenges which often happened during QOL-AD questionnaires.

Broader eligibility criteria

Network Partners delivering MCST focused on involving people living with mild to moderate dementia but were flexible and accepted all who they felt would benefit from the sessions, including those without dementia diagnosis but who experienced memory problems. However, MCST groups varied greatly in how mild or advanced dementia clients had. Where they included clients living with very mild or more advanced dementia, this occasionally created challenges. Those with very mild dementia or mild cognitive impairment sometimes found MCST activities too basic, whereas those with more advanced dementia sometimes struggled to participate, which could affect the group dynamic.

In addition, other eligibility criteria were considered in some cases. For face-to-face sessions, some partners discussed client mobility, ability to use the toilet independently, and being able to hear and see. However, application of these criteria varied. For example, while one Network Partner only accepted people who could use the toilet independently, another accepted clients with personal care needs (which staff found challenging and felt unprepared for).

In the case of online sessions, partners also varied in how they approached clients' access to digital equipment. While one partner lent devices, another partner only accepted those with their own equipment. In addition, clients' ability (and willingness) to join online sessions was a common criterion for online MCST. At the same time, this was not always applied with the same consistency. For example, one Network Partner reported how their online group included a client who disliked online activities, who subsequently dropped out.

The experiences above highlight a diversity of approaches to eligibility criteria, but also the need to consider implications of different approaches and the requirements and challenges they can create for staff.

3.1.3: PRACTICAL CONSIDERATIONS AND DECISIONS DURING THE SET-UP PHASE

In addition to recruitment and client assessment, there were other practical issues and decisions MCST partners had to consider during the set-up phase, but sometimes also during the service delivery.

Set-up timescale

Some staff respondents who delivered MCST at the start of the programme in 2021 felt that MCST project set-up of 3 months was very intense. They felt they needed more time to complete all set-up activities, including staff training, client recruitment and assessment, choosing the venue or familiarising clients with Zoom. This feedback did not surface in discussions with partners who set-up their MCST in 2022 and 2023, as partners were given more flexibility with regards to their start and end dates (up to 6 months), based on the programme's learning from the early cohort.

Making MCST groups accessible

Client feedback on accessibility of venues for face-to-face sessions was positive, as all venues were felt to be accessible and suitable. Most clients also reported they were able to travel to the venues easily, as they were either taken by relatives or Age UK-organised transport. However, a smaller number of clients and carers highlighted transport as a problem (as mentioned earlier) due to the following main issues: poor transport links to the venue; carers struggling to find the time to drive clients; or unreliable community transport. Those struggling with transport wanted to have access to free or affordable and reliable community transport.

"The venue's really good too because it's nice and flat, there's no steps and stairs to manage and the toilets are accessible. They have disabled doors there so you can get in but you can't get out without pressing the button, so nobody can wander off. And it's nice and light and bright." - Client

"We have an arranged community car scheme but they prioritise medical appointments so people can't come because they can't get transport. That is a real issue for us." - Staff

To enable access to online MCST, many clients needed technical support during the set-up phase, although there were some variations in what and how this was provided:

- In many cases, technical set-up support was delivered face-to-face in clients' homes. However, where this wasn't feasible, some partners provided support remotely, over the phone and online.
- The extent of support provided varied depending on the needs of clients and their level of digital skills. At the minimum, staff checked the internet connection, camera and sound were working and taught clients how to use Zoom or Teams and some key in-built features. In some cases, however, staff provided more support, for example, set-up email addresses for those who did not have them or lent them digital devices.

Most clients and carers in the qualitative sample were very positive about the support they received to be able to access MCST online.

Choosing a venue

Staff highlighted some other practical considerations important when choosing a venue for MCST groups:

- **Facilities:** Staff generally felt venues they used were suitable in terms of facilities, for example, having access to technology or kitchen. In a couple of cases, staff reported their venues had some limitations affecting what they could deliver or how; for example, not having the technology to show some activities on screen or not being able to do painting because they had no access to a sink.
- **Size of the room:** One staff respondent suggested partners delivering MCST should allow for their groups to grow over time when choosing a venue. Their room size was suitable for their initial group, however, it became too small as the group grew bigger.
- **Cost:** Those able to use Age UK or other venues for free appreciated making considerable savings. Conversely, those using external venues often found them costly.
- **Other issues with using third-party venues:** A couple of staff respondents reported some difficulties when using third-party venues, because they depended on others for access to those venues and fixing any problems that emerged. For example, one MCST group was initially hosted in a care home, but as the care home kept getting closed due to Covid-19 outbreaks, staff eventually decided they had to move to another venue. In other cases, a couple of MCST groups were temporarily unable to use their venues due to problems with air conditioning or heating.
- **Area where the venue is located:** Some partners stressed the importance of considering the area where the venue is located to ensure there are things for carers to do while waiting for clients, for example, shops, cafes etc.

"It's got a feel of a classroom, in a really nice way. The ladies who attend, they've put their photographs on the wall all around. There's a whiteboard that they use, if they're doing pop quizzes and that they've got a board. It's a lovely space with windows all along one side, so it is quite small intimate room, it's nice." - Carer

Timing and duration of sessions

Staff, clients and carers also commented on considerations when deciding on the time and duration of MCST groups:

- **Timing:** There were varied opinions in this respect but main considerations were: not starting too early in the morning to allow enough time for people living with dementia to get ready; and not finishing too late, as some older people may dislike travelling in the dark, especially in winter. Late morning sessions were sometimes also appreciated because staff and carers felt they put clients in a good mood for the rest of the day.

- **Duration:** Most MCST sessions were 1.5-2 hours long, which allowed some extra time for socialising before and/ or after the group. Where sessions were 2hrs long, most staff and carers also felt this was long enough to also allow carers to use that time productively. Where sessions were shorter, for example, 1-1.5 hours, a few carers commented this was too short to allow them to use that time.

  While 1.5-2-hours long group sessions were common, there was also a lot of variation in how long the sessions were. For example, most staff thought that shorter sessions worked better online, e.g. 45 minutes to 1 hour, as they thought clients would find it difficult to sit in front of a computer for longer. However, the shorter length also meant there was less time for socialising, which was an important benefit clients enjoyed. This was raised as an issue by a few online MCST clients who wished there was more time for socialising at the end of the session.

  There were also a couple of partners who built-in their MCST sessions as part of their day service, either at their day centre or as a day out. Staff at these Network Partners stressed this provided more respite to carers and more independence to clients.

MCST group formation

Discussions with staff also highlighted considerations and decisions they had to make regarding the formation of MCST groups:

- **Grouping clients:** Some partners explained they tried to group clients with similar levels of dementia, so that group activities would be easier to run. Sometimes this was also because of a concern that clients living with mild dementia may feel uncomfortable seeing more advanced dementia. For many other MCST groups, separating clients by the extent of dementia wasn't practically possible. While this could sometimes be challenging in terms of pitching activities to suit everyone, some benefits were also reported from these mixed groups. For example, clients living with mild dementia appreciated being able to understand more about dementia by meeting people living with different types and extent of dementia.

- **Group size:** MCST groups typically included between 4 and 8 clients. Groups up to 8 clients were felt to be small enough to allow everyone to participate in face-to-face groups and build relationships, which clients liked and appreciated. While this was common set-up, group size also varied.

  At one end of the spectrum, a couple of Network Partners ran larger face-to-face MCST groups and thought they could accommodate up to 12 clients per group, provided staff were supported by volunteers. At the other end, smaller groups were sometimes seen as more suitable. For example, a staff respondent thought that groups needed to be smaller if clients had more advanced dementia, for example, including up to 5 clients. Also, smaller groups were felt to work better online (Age UK recommended up to 4), as then clients could see everyone well, which was important to them. Some respondents felt that such smaller groups made MCST sessions more personalised, as staff could tailor individual activities more to clients and had more time for them individually.

  However, some clients and staff highlighted the risks of smaller groups. With attendance fluctuating due to ill health and some clients dropping out for the same reason, small groups were sometimes reduced to 2 people or even just one client. To avoid those risks, clients in those groups wished their groups were bigger at the outset to be able to manage the oscillations in group numbers. Another suggestion was to open groups to new members who would replace those who left.

"It feels OK but I'm happy when there's more people. Sometimes some of the others haven't come and it's nicer when they are all there. I think ten people would be OK." - Client

Free or paid-for activity

Many partners offered the first 24 weeks of MCST free of charge to clients, however, some provided MCST as a paid-for activity. Others asked for a small, voluntary donation per session. With the end of the 24-week programme, some of those who offered this service for free were thinking of starting to charge a fee to allow their groups to continue.

There was considerable variation between different partners in what price they charged or thought they could charge, ranging from £5 to £25. While many felt that charging £10 per session was or would be acceptable to their clients, some staff thought that people in their area would not pay more than £5 per session. In one case, staff also felt it would be unethical to charge more than a very small fee because their goal was to support people on low income. Clients and carers, for their part, mostly thought that paying £5-10 was reasonable and what they could afford, once they added that to the cost of transport.

In setting the fee, staff were trying to balance not making MCST unaffordable with enabling their MCST groups to continue once the initial funding was over. In most cases, however, staff explained they would need to secure additional funding to cover the costs of the programme, in addition to charging a small fee.

"In (this area) our main focus is aiding people who are on lower income and gaining them benefits so that they can support themselves. So, for us to go in and charge a really high fee for a service we provide doesn't fit with our ethos and the way we work." - Staff

3.1.4: STAFF TRAINING

Staff were required to attend a training in delivering the MCST programme, as well as additional training focusing on understanding dementia and working with people living with dementia. Interviews with staff explored their experiences of, and views about, these different training sessions they attended to understand the extent to which the programme achieved its objective to provide staff with the knowledge, skills and confidence needed to deliver MCST sessions.

MCST programme training

Almost all staff interviewed for the evaluation attended the MCST training, which they were expected to do as part of their involvement with the programme.[2] There were a few exceptions to this, for example, a couple of staff members attended this training in their previous role. Also, where there was staff turnover, a couple of staff respondents explained they missed the initial training but the learning was passed on to them by a colleague who was trained and who co-delivered MCST sessions with them.

Staff who completed this training felt it provided a helpful step-by-step guide and supported them with questions they had. Many felt that the training provided them with the knowledge and evidence about MCST; that it was clearly structured and facilitated well; and gave them opportunities for questions and discussion. Video clips were highlighted as particularly useful in bringing activities and group facilitation to life, although a few staff felt the clips could be more current. Some also enjoyed being able to meet other partners delivering MCST sessions and liked sharing information and tips in break-out groups.

"It gave us the tools and confidence to be able to run the group." - Staff

Staff also identified areas of the MCST training that could be improved:

- **Practical learning:** Some thought that the MCST training should be more interactive, practical and focus more on the delivery. For example, staff expressed interest in observing a MCST session as part of their training. Where this was arranged by individual partners, staff found that extremely useful for preparing their own sessions. Others suggested that the training should include input from Age UK staff experienced in delivering the MCST programme, for example, they could share their experiences and learning.
- **Adapting the programme:** Staff wanted more guidance on how the programme could be adapted depending on clients' interests, different levels of dementia and needs, cultural diversity, as well as to work for online MCST sessions.
- **Credibility:** A few staff respondents considered the issue of credibility of their skills and knowledge following the MCST training. For example, a respondent suggested that staff should be issued certificates, which they could display to help reassure carers about the credibility of the programme. Other respondents explained that some staff found the therapy status of MCST daunting, as they felt they lacked the training and credibility as therapists. Respondents suggested this should be addressed as part of the training, so the staff are reassured about being able to deliver the therapeutic aspect of MCST.

"I thought it was really useful to get an idea of how the sessions were run. Maybe we could have had some people that had already been involved with the sessions to give us some more ideas for what we could have done, so people from cohorts 1 and 2. It might be useful to talk about what had worked for them." - Staff

"It was a lovely training and it covered the majority of what is needed. It's just that MCST is a slightly funny thing because it's classed as a therapy and everybody talks about it in a very professional capacity, so you feel slightly underequipped to run something like that." - Staff

Staff across the programme were also very positive about the MCST manual, *'Making a difference 2'*, and reported they used it all the time. Staff appreciated the manual gave them ideas for activities and helped them structure their sessions. A few respondents suggested the manual could be further improved by making it less prescriptive, providing guidance on how to adapt the programme to different groups of clients and delivery online, and ensuring that users could access all the resources listed in the manual.

'Learning from Living with Dementia' (Train the trainer course)

Staff who attended this training[3] were often enthusiastic about the knowledge and understanding of dementia it provided, as well as how the training was delivered. The training was seen as informative, useful and interesting and staff felt it helped them to understand people living with dementia. Many liked that it was based on lived experience of people with dementia and particularly found the videos of people living with dementia impactful. Some staff also appreciated that the training focused on what it was like to live with dementia, the wellbeing of people living with dementia and a person-centred approach to working with people with dementia. In terms of the training delivery, staff felt the length of the training was suitable, enjoyed its interactive nature, and found it useful to be able to practise their presentation skills.

"It gave insight into people and their minds, and the way everyone's dementia is different. How to work with people with dementia, and particularly about finding that path of how much support to give while also giving them some independence. The way it was delivered was great, the length of the course was perfect. We've gone on to the deliver the course to 15 of our staff members and the feedback has been amazing." - Staff

"I found that really useful, I'm quite looking forward to cascading that down. It's quite a long intensive course but it was necessary for it to be like that. It's very rare to practise your presentation skills and get instant feedback and watch other people." - Staff

A few staff raised some considerations for future delivery of this training:

- **Sensitive issues:** One staff respondent suggested the audience should be warned that some people may find the videos upsetting, for example, if they had personal experience of dementia in their family.
- **Timing of the training:** Another respondent stressed the importance of providing this training to staff before they started delivering their MCST programme (as they attended this training half-way through the programme).
- **Medium of delivery:** There were mixed views on whether the training worked well online or not. While some staff thought it did, others wished the training was face-to-face.
- **Duration:** Some commented that although helpful, the training was tiring. This comment was made about different formats: both where the training was delivered online over one day and where it was split over two days.
- **Repetition and overlaps:** A couple of respondents felt there were parts of the training that were repetitive (as well as overlapping with the Dementia eLearning training).

In terms of staff confidence to cascade the *'Learning from Living with Dementia'* training to others, respondents generally felt the training equipped them with the knowledge and the tools to train others. However, there were still some variations in how staff felt about delivering the training. Some staff found the idea of training others personally daunting, particularly the length of the training they were meant to deliver. The length of the training was also seen as challenging in terms of the time commitment for those attending, given the time pressures for staff and volunteers. Conversely, other staff were enthusiastic about cascading the training to others. For example, a Network Partner was planning to deliver the training not only to staff and volunteers, but to wider stakeholders in their local area, including carers, GPs and other relevant organisations. Also, where the training had already been cascaded, respondents reported it was very well received by other staff.

"In this cohort we decided we're going to open it up to anyone who wants to come, we had people from care homes, unpaid carers, people from GP surgeries come along." - Staff

Dementia eLearning

Most partners in this qualitative sample reported that at least some staff within their organisation had completed the Dementia eLearning training and that it was being rolled out to other staff.[4] There was a mixed reception of this training, with both some criticisms and positive feedback. Staff from the first cohort of the MCST programme sometimes felt this training was too text-heavy and lacked more interactive elements. Some also pointed out the training took longer than stated and overlapped in content with *'Learning from Living with Dementia'*.

Staff from the later cohorts gave more positive feedback on this training (so may have been commenting on a revised version of the training). All staff respondents found it informative and useful to embed knowledge about dementia and some reported positive feedback from volunteers. Some highlighted particular elements of the training they liked, for example: videos breaking up the text and information being concise and easy to navigate.

The only issue a few respondents raised was the time within which partners were expected to meet their targets for their staff completing the training. The respondents suggested that a longer period may be needed to reach these targets. In addition, a respondent thought it may be helpful to consider whether there were some types of staff who did not need to complete the training, for example, staff working in administrative roles. Some also felt that expecting volunteers to complete this training may be excessive in certain situations.

"It was quite informative, because I've only been in the role for just over a year. It's laying the foundation that I need and gave me the confidence to use those skills." - Staff

3.2: MCST PROGRAMME DELIVERY

3.2.1: MCST ACTIVITIES

Overall feedback on MCST activities

Across the programme, there was a recognition from both clients and staff that MCST offered a wide range of activities that could be matched to different people's interests. Clients reported they enjoyed most activities and found them fun and stimulating and the following factors contributed to this:

- **Variety:** Clients, carers and staff felt there was something for everyone in the MCST programme, so were happy to take part even if a particular activity was of less interest to them.

"They've got different themes which cover quite a wide variety of subjects, childhood, household items or treasures, it really does cover a lot, they've had numbers recently as well. Lots of different aspects of things to keep the mind active and keep promoting using the mind." – Carer

"Because there's variety, it's ok to do something out of your comfort zone and new." – Client

- **Suitable difficulty:** Clients also felt that activities were set at the right level, providing some challenge but without being daunting. Most thought that facilitators managed different needs and levels of dementia within the group well.

  A few clients, however, felt that certain activities were too basic or childish for them, highlighting the challenge in balancing different levels within the groups. This was particularly the case with some recently diagnosed people who felt some activities were not challenging them, but still enjoyed them for social reasons. Some staff also commented that activities needed to be perceived as 'adult' and not 'childish' or 'patronising', as well as needed to cater for different levels of dementia.

"I've done some of those (physical activities). It was OK. I felt some of it was a bit childish in some way, but I did enjoy it." – Client

- **Teamwork approach:** Many carers and some clients commented how older people living with dementia were more likely to engage in doing activities within the MCST group setting rather than alone or with a carer at home. Doing these activities in a group of familiar people who supported each other helped clients engage and stretch themselves.
- **Enabling clients to identify and use their skills:** Many clients enjoyed seeing they were still able to do certain activities. Sometimes they also discovered old skills and felt very happy finding they were still able to use them. Overall, the range of activities supported older people living with dementia to identify, focus on, and keep using the skills they still had.

"We have a sing-along and a picture to colour in, questions on this picture and answers. It's very, very interesting, very likeable. It's a very worthwhile pastime, very good. It's keeping our brains awake." – Client

- **Boosting client confidence:** Seeing what they were able to do helped many overcome anxiety over not being able to communicate and complete various tasks. This gave clients a sense of achievement and boosted their confidence to interact with other people.

"It just makes me happy and joining in, thinking how lucky I am that I can do what I can, you know. The brain seems to keep working!" – Client

- **Therapeutic aims:** A few clients approached MCST activities as a learning and growing process; almost as work they had to do to achieve the desired therapeutic effect. This gave them motivation to focus and engage with activities in their MCST group. This was echoed by some carers and staff, who also stressed the focused, intense and therapeutic nature of MCST sessions.
- **Tailored approach:** Staff felt that most activities worked well, but also reported they sometimes adapted the programme depending on their group interests. For example, they may have decided to sing only once during the group session if their group did not like singing. Clients commented on this aspect of the programme too and appreciated that sessions were adapted to reflect their interests.

"With our more advanced group, for some things we've thought well that's just not going to be suitable, we need to find a way to tailor it to that group and it is hard to know what is acceptable within the MCST standard." - Staff

Feedback on different types of activities

Some activities were singled out as having particular benefits:

- **Word and other games, quizzes and competitions:** In addition to providing cognitive stimulation and social interaction clients enjoyed, these activities were felt to also offer a sense of achievement and build confidence in clients. Clients also enjoyed the competitive aspect of some of these activities.

"The other week mum came in the most animated I've ever seen, they'd done word problems, mum loves that and they'd done something like with word association. She was on fire when she came in, telling me all about it and I had to do with her, I'd just come in from a day at work and she did it quicker than me because she's really bright." - Carer

"It sparks off happy memories for them and sparks off conversation. Some of the (old) items we didn't even know what they were so it was like, 'Does anybody know what this is' and it got everybody thinking." - Staff

- **Remembering the past:** Clients enjoyed topics and materials that helped them remember and share past memories, which some felt made them feel better about their memory. In the context of their short-term memory problems, remembering things from the past made clients realise they could still use parts of their memory and appreciate abilities and skills they possessed. This finding was also echoed by staff who commented how clients enjoyed reminiscing.

The research also highlighted some challenges in discussing the past where clients did not necessarily have shared past experiences or these were traumatic. For example, some staff felt that the materials and sessions covered by the MCST manual and programme were overtly White British-focused and lacked guidance on how to make the programme more culturally diverse. They found that clients from other ethnic backgrounds or who were born outside of the UK sometimes struggled to join, if sessions weren't adapted to allow them to bring in their different experiences in discussions. To overcome this challenge, staff sourced images linked to those clients' cultures/ countries and one also used Google Translate in sessions to sometimes find the words in the clients' native language. In another case, a partner ran a Gujarati-speaking MCST group, where clients enjoyed being able to remember aspects of their shared culture together.

In addition, a few staff respondents noted the potentially sensitive nature of activities focusing on clients' past family experiences, where these were traumatic. The staff respondents warned against doing these activities early on in the process, before clients were familiar with the group. One staff respondent also suggested having break-out spaces where someone could discuss this topic more privately, and another thought staff should warn clients that such topics could trigger upsetting memories.

"I found childhood was a difficult one because it could trigger some memories which weren't always the best memories." - Staff

- **Discussions:** Any activities that involved discussion and interaction with other clients were much appreciated, as clients enjoyed socialising and felt this improved their confidence to speak and participate in other social situations.
- **Physical activity:** Clients and staff were mostly positive about sessions that involved physical activities and felt these energised the group. A staff respondent also pointed out that physical games can be a good ice breaker.
- **Visual and music / sound / sensory activities:** Some staff thought that using visual aids and music was very important as it offered more opportunities to participate to those older people who may struggle with verbal communication. Staff also thought that using music at the start was uplifting and helped bring clients into the session. Examples of visual aids and sensory activities staff found clients liked included looking at the photos of places and landmarks from their local area or being asked to identify different smells.

"We do a lot of interactive presentations and we utilise old film footage from around the local area, pictures and they can be very powerful. The discussions it will bring, really powerful." - Staff

"Music works really well because it relaxes people and lifts their mood and also triggers memories." - Staff

Variations in clients' experiences of activities

Which activities clients enjoyed varied from group to group, depending on their interests. For example, a staff respondent reported how clients in their groups enjoyed crafts, gardening, games and some basic cooking, whereas other staff from a different Network Partner commented how their clients enjoyed decorating biscuits and any competitive games.

While no respondents were negative about any activities, many clients noted they were more interested in some activities than others. However, everyone recognised that the programme needed to cater for different interests and were generally happy to participate even if a particular activity wasn't to their taste. Some staff respondents or carers also suggested clients disliked activities that reminded them of things they were struggling with. The types of activities that prompted such response varied and were by no means universal across clients. For example:

- Cooking reminded some of domestic tasks they were no longer able to do, whereas others loved their session on cooking.
- A carer thought their mother disliked discussions of current affairs due to lacking awareness of the news, whereas many other clients enjoyed this activity and felt it connected them to the wider world.
- Orientation and using maps were found to be too difficult for some clients with more progressed dementia, whereas others enjoyed being able to look at the places where they grew up in or other places of interest.

There was further one suggestion for how the range of activities could be improved. Specifically, a carer suggested that trips out would further enrich MCST activities on offer and be beneficial for clients, but recognised this may be challenging to organise.

"They have got it spot on. The only thing would be some trips and to go some external places, so it is not just in the centre. That would be the only thing I would say. I can see there would be challenges with that though." - Carer

Adapting MCST activities to online delivery

To deliver the MCST programme online, staff had to come up with ways to adapt activities and support clients to engage with them online:

- Activities were primarily adapted by using Microsoft PowerPoint to show pictures and text to clients. Some partners also used other digital media, for example, YouTube videos where appropriate.
- Numbering pictures and text, for example in a quiz, was felt to be helpful as it allowed clients to more easily refer to what they were seeing online.
- Sending clients physical materials needed for the sessions also allowed clients to engage with activities at hand.
- Using pre-set breakout rooms was helpful, as it made it easier to address issues that individual clients may have by discussing it privately in a breakout room rather than disrupting the main session.

Staff, clients and carers also shared feedback on the different types of MCST activities that worked well online, although there were some variations in experiences and views, as with face-to-face sessions:

- **Activities that worked well online:** Staff felt that activities that involved discussion worked best online, as they were suitable for that medium. In some online groups, creative activities also worked well, as clients enjoyed discussing images and engaging with creative tasks. Where clients lived in different parts of a country, they all enjoyed discussing weather and local points of interest with others in their group.
- **Activities where there were mixed views:** Staff views varied on how well physical activities worked online. Some staff felt they couldn't do some physical activities from the MCST programme. Others found that armchair exercise worked very well online (delivered either by staff or via YouTube video). Some clients who did armchair exercise also enjoyed that and found it stimulating.
- **Activities more difficult or less engaging online:** Some activities were felt to work less well online, for example, some staff mentioned singing didn't work, as clients were out of sync online. In addition, some staff found the session on orientation and maps challenging online. One staff respondent thought that trying to get clients to use maps and work out routes – without staff being able to see what they were doing and help them – was difficult online.

   Some staff also thought that sessions that involved practical or sensory activities worked better face-to-face. For example, a staff respondent who delivered both online and face-to-face MCST groups felt that the sessions on household treasures or cooking and tasting food worked better face-to-face, as clients could see and engage with the objects/food better.

In addition, some staff noted that certain aspects of the process were more challenging online than face-to-face:

- Being able to see client body language and their reactions;
- Being able to manage situations where clients talked at the same time;
- Being able to chat and socialise informally in addition to MCST activities;
- Showing presentations or other visuals as sharing screen meant clients found it more difficult to see others in the group, which staff felt some clients found confusing.
- Managing client behaviour where they were not used to communicating online, for example, pulling faces at other people's comments without thinking they could be seen.

3.2.2: DELIVERING MCST SESSIONS

Beneficial programme features

Clients, carers, and staff identified particular features of the MCST programme they enjoyed and saw as critical to its success:

- **Group dynamic:** All respondents highlighted the social aspect of MCST groups as extremely valuable to clients. Clients, carers and staff often commented how clients made new friends, looked forward to seeing them, remembered each other's names, and became more socially confident and engaged. The social benefits were more linked to face-to-face MCST sessions, which were seen as better at enabling socialising than online MCST. However, some online MCST clients also commented how they became familiar with people in the group, felt comfortable talking to them and looked forward to seeing them. In one case, a partner delivering MCST online organised a trip to a museum for their online clients, to provide opportunities for socialising.

  The research found that MCST groups provided safe space for clients to socialise, compared to how they felt talking to people otherwise. Some clients and carers commented how this was because everyone in the group was in a similar situation, so they understood each other and what they were going through. In this safe space, clients stopped feeling vulnerable and could relax as they felt no one would mock them, be impatient with them or patronise them. A few clients commented how they could feel 'ordinary' in this group, as they were treated like anyone else and not reduced to a person who had dementia. MCST groups also provided a community for clients and carers, where some felt they could learn from others about coping with dementia.

"They are all very friendly and we all have quite a lot of fun, it's funny; there's a lot of laughing which is good for you!" - Client

"You feel part of something and it's nice to be able to talk about how they feel really." - Carer

- **Routine, structure and regularity:** Having the same staff and structure of MCST sessions was reassuring to clients and helped them to get used to sessions and feel comfortable knowing what to expect. In addition, some carers and staff felt that having regular, weekly sessions was also critical to older people engaging in activities and developing relationships with others in the group. Knowing that sessions will be regular and go on for at least 24 weeks also made some feel more relaxed and reassured.

"The routine is quite nice... We start off with weather, day etc. The equipment's good, a series of three circular tables, with your name thing. It feels like home, feels familiar, it's not daunting and it's not regimented." - Client

- **Staff manner:** Clients and carers were full of praise for staff delivering MCST sessions, describing them as:

Caring	**Kind**	**Supportive**	**Encouraging**	**Non-judgemental**	**Patient**
Attentitve	**Respectful**	**Welcoming**	**Considerate**	**Thoughtful**	**Professional**
Well-trained	**Knowledgeable**	**Skillful at conversation with people with dementia**		**Informal but organised**	

  Clients noted how staff always made sure everyone could participate but did not put pressure on individual clients to speak. A few also commented how staff always addressed them first rather than their carers, which they found was rare otherwise. Some enjoyed that staff helped them do things rather than do it for them.

"I can't describe or praise it enough in a way for being non-judgemental and encouraging people to feel confident to talk when they may not do otherwise." - Client

"Staff are skilled at getting people with dementia to talk and participate." - Client

- **Supporting materials:** Some clients and carers reported receiving supporting materials, for example, information about the next session, tasks to complete at home, information for carers about group activities after the session. Handouts such as this sometimes enabled clients and carers to carry on with some activities and discuss them. Where carers did not know what activities clients did, they suggested this information should be provided to them after each session. Some staff also reported clients enjoyed being given resources to take away after sessions, for example, pictures they used or produced.

"The only thing from my perspective is that it's a bit of a black hole in terms of what goes on in there; that's fine, it's their time, but I feel like it might be a bit helpful to have … a more formal way of knowing what's happened in the sessions; how could we top it up, are there any lessons we could learn? That's the only tweak I would make." - Carer

"(It's very helpful) partly so that dad has an idea of what going to be in so he can prepare a little bit for it but it helps me as well so I can ask him what kind of things have they done and it helps to keep that conversation going later on as well." - Carer

Challenges in programme delivery

Some staff identified particular challenges in delivering MCST sessions:

- **Managing differences within groups:** Some staff found it challenging to manage different levels of dementia and ability in the group and ensure activities were appropriate for everyone. For example, one staff respondent found that activities that were fine for those with mild dementia were sometimes difficult for those with moderate dementia.

  Other staff reported situations where other differences within their group posed challenges. Where clients were in a minority in terms of their age, gender or ethnicity, this sometimes created barriers to participating or made them feel self-conscious. For example, a carer said that a 50-year-old woman with dementia stopped attending their MCST group, as she felt she didn't fit in being much younger than other clients who were in their 70s and 80s. Similar comments were made by some clients, for example, a male client pointed out it can be a bit difficult because he is the only man in his group.

"When you're working with people across a wide range of ages or cognitive abilities it really does challenge you to come up with a programme that engages them all; for example, if we're going to do a wordsearch, I have to challenge some people with good cognitive abilities, as well as some colouring at the same time for those who feel a wordsearch would be too much." - Staff

- **Time-intensive aspects of preparation:** Some staff highlighted aspects of preparation for sessions that took most time, so which should be factored in planning the resource for the service. Some who delivered online MCST sessions found preparations took longer than anticipated, because staff needed to create Microsoft PowerPoint presentations for each session. In face-to-face MCST sessions, some staff commented preparation could take longer when they needed to source props and materials for the sessions. To help new partners deliver MCST, there was some interest in potentially sharing resources previously used in MCST sessions across the Age UK network.

"We work full-time but I don't think they realise how long it takes to put the sessions together and we often work outside of working hours for session planning." - Staff

- **High support needs:** Staff also emphasized that clients in MCST groups required different types of support from staff and volunteers ahead of, and during the sessions, to be able to participate in the programme:
- ◦ **Reminders and check-ins:** Staff sometimes mentioned they had to call clients ahead of their sessions to remind them to come and check how they were feeling. This was the case for both face-to-face and online sessions.
- ◦ **Support in-sessions:** MCST group sessions required capacity to provide extra support to individual clients where needed. Therefore, they were typically delivered by two members of staff, who were in some cases supported by volunteers. Where volunteers were present, staff found this was very beneficial. In face-to-face groups, volunteers provided additional support with activities and reassurance where required. In online groups, volunteers (or additional member of staff) sometimes helped solve technical problems individual clients had, so this did not disrupt the running of the session. One partner delivering online MCST also stressed the importance of having break-out rooms to be able to support individual clients in-sessions.
- ◦ **Care needs:** Most partners did not report challenges in meeting clients' care needs during the sessions, however, this was raised as an issue in one instance. One partner reported their MCST groups included some clients who required handling and moving support, as well as support with toileting. Staff found this challenging as they did not have moving and handling training or bodily fluids training, which they felt staff would need in the future.

"(In the future, we'd ensure) training for staff and volunteers around bodily fluids, handling etc. We have four volunteers who all used to be nurses on the dementia ward, so they used their experience, but there was no guidance from MCST or Age UK that these issues might be a problem (movement, walking, personal care)." - Staff

3.2.3: FUTURE PLANS FOR MCST SERVICE

Staff interviewed in qualitative research all wanted to continue offering MCST. The main reasons for wanting to continue were as follows:

- Staff recognised its value and benefits for older people living with dementia or cognitive impairment.
- Some staff also pointed out that the need for such support did not disappear after 24 weeks, so they set out from the start to carry on with the programme as long as clients wanted and were able to access.
- Others noted that losing MCST would leave a big gap in post-diagnosis support in their area.

However, many staff acknowledged the continuation of their MCST service depended on whether they could secure further funding. Most also assumed that MCST would be likely to become a paid-for service to be sustainable.

"The need isn't going away after 24 weeks and all of our clients seems to enjoy coming so much it seems a shame to just stop and then they have nothing; there is very little support out there and we don't have anything else like that in our area. That's why we've just kept going." - Staff

"It would be such a shame (not to continue). A few of them (clients) were nearly in tears when they heard it was coming to an end." - Staff

Like staff, all clients and carers in this qualitative sample wanted their MCST groups to continue past the initial 24 weeks. Clients and carers were also sometimes concerned about the impact of the programme stopping:

- Clients whose groups stopped felt they lacked stimulation and missed seeing their new friends. Some clients and carers also worried about clients deteriorating once the sessions had stopped. While some clients and carers planned to find another activity to replace MCST that ended, others were concerned they will be unable to find something else.
- Similarly to staff, some carers stressed that the need for support did not stop at 24 weeks and one respondent suggested that a lack of follow-up after 24 weeks was the only flaw of the MCST programme.

"The model is brilliant but the follow-on isn't thought out, what happens afterwards. There is natural drop—out and one accepts that, because two or three people have had to go into residential care during the time that the groups happened. But there's always been a feed-in of new people." - Carer

"We will do anything we can to help. We see real value in it. I know from others who are dropping off they do as well, everyone is on same page, its great that it exists, and we are really lucky to have access to it." - Carer

"I was heartbroken when the sessions ended as they really look forward to them. I think they should be funded, and they should continue." - Staff

Given the perceived importance of the service, carers and clients sometimes considered continuing to meet even if partners could not carry on with their groups. In two cases, carers and clients were planning to meet socially once a month. In another case, they hoped to carry on with MCST activities on their own. One of the carers in that group consulted Age UK MCST staff and was eager to learn and facilitate group sessions in their home. Clients and carers from this group felt very motivated to make their own MCST group a success.

In addition, over a half of the programme partners have continued to deliver MCST groups beyond the funding period of the programme.[5]

- 38 out of 64 partners were delivering their MCST service in November 2023, past the end of the funding and initial 24-week long programme.
- Across these 38 partners, 84 MCST groups were being delivered;
- 5 more partners were planning to re-start their MCST groups in the coming months;
- 11 partners either reported they lacked finances to continue or decided to provide other dementia support services (e.g. a 6-week long CST programme instead of MCST).[6]

4: Impact evaluation: what difference face-to-face and online MCST made

4.1: IMPACT ON CLIENTS' QUALITY OF LIFE

As part of Outcome 1, the aim of the MCST programme was to improve wellbeing of people living with mild to moderate dementia. The programme has achieved this outcome based on both quantitative and qualitative findings which are discussed below.
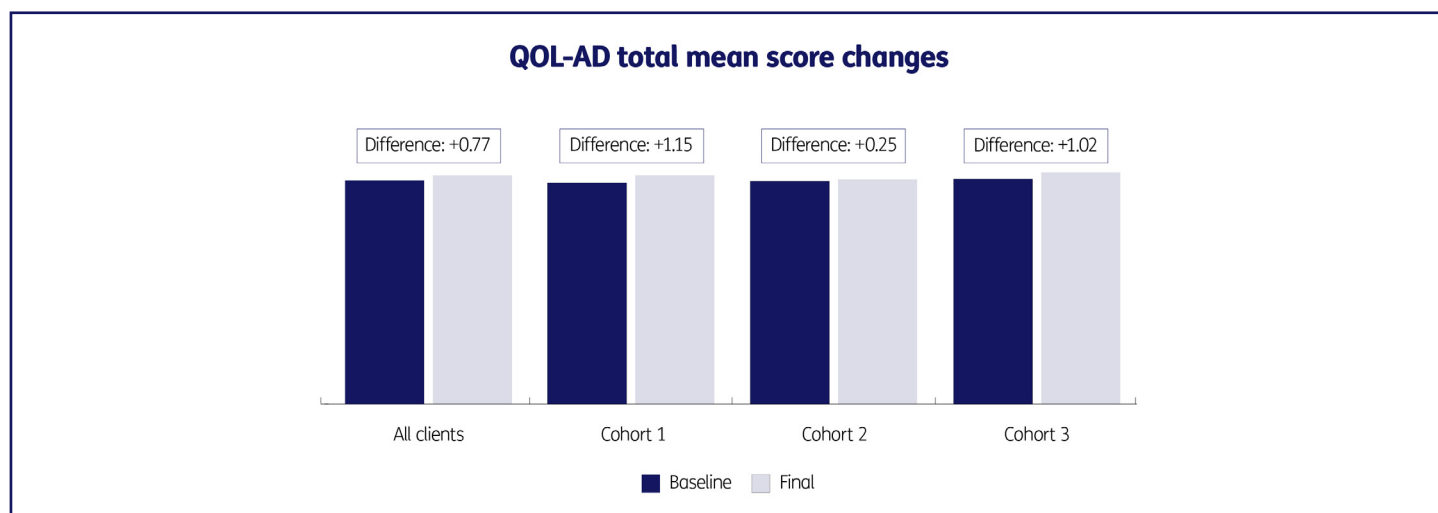
Quantitative findings

The QOL-AD questionnaire is made up of 13 individual questions, each scored on a scale from Poor to Excellent, where Poor is scored with 1 point and Excellent with 4 points. The total QOL-AD score is achieved by adding up the scores for the individual questions. The minimum total score is 13 and the maximum 52. Higher total QOL-AD scores indicate higher quality of life and vice versa. To assess whether quality of life has improved or worsened following an intervention, researchers would compare mean total QOL-AD scores at the start and at the end of the intervention. Some scholars have also argued that it is important to look at the changes in individual people's total scores, as there is typically a lot of variation between different people in a group in how their scores change over time.

However, understanding what these changes might mean and how significant they may be for people living with dementia poses some challenges. This is because there is a lack of agreement on what constitutes the minimum important difference, that is, the minimum improvement that would be considered worthwhile for the person living with dementia.[7] For example, some scholars have argued that a difference of 3 in total QOL-AD scores should be seen as '*minimum significant difference*,'[8] whereas others suggested that may not be appropriate for assessing all interventions and may be higher than the rate of decline in quality of life of people living with dementia.[9] Given this lack of agreement, previous studies of the impact of CST and MCST can provide a relevant reference point for interpreting the changes in mean total QOL-AD score identified in the evaluation.

Previous studies found that CST improved quality of life in people living with dementia.[10] The original randomised control trial (RCT) of CST found that the mean total QOL-AD score in the MCST group improved by 1.3, whereas it declined in the control group by -0.8.[11] A subsequent study of the effectiveness of MCST was carried out with people with dementia who previously had a course of CST and found that MCST impacted positively on quality of life of people of dementia.[12] The mean total QOL-AD score in the MCST group increased by 0.45 after 6 months of the programme and was 1.78 points higher than that in the control group.[13]

In line with the findings above, this evaluation found that the total QOL-AD score for clients in the Age UK's MCST programme increased, suggesting an improved overall quality of life following the intervention. Specifically, the mean total QOL-AD score was 0.77 higher at the end of the programme than at the start. The increase was higher in some cohorts than others, with cohorts 1 and 3 showing greater improvement of 1.15 and 1.02 points respectively, broadly in keeping with the 1.3 increase found in the original CST trial. The chart below shows the changes in mean total QOL-AD score for all clients in the programme and for cohorts 1, 2 and 3 separately.

QOL-AD total mean score changes

Difference: +0.77 — All clients
Difference: +1.15 — Cohort 1
Difference: +0.25 — Cohort 2
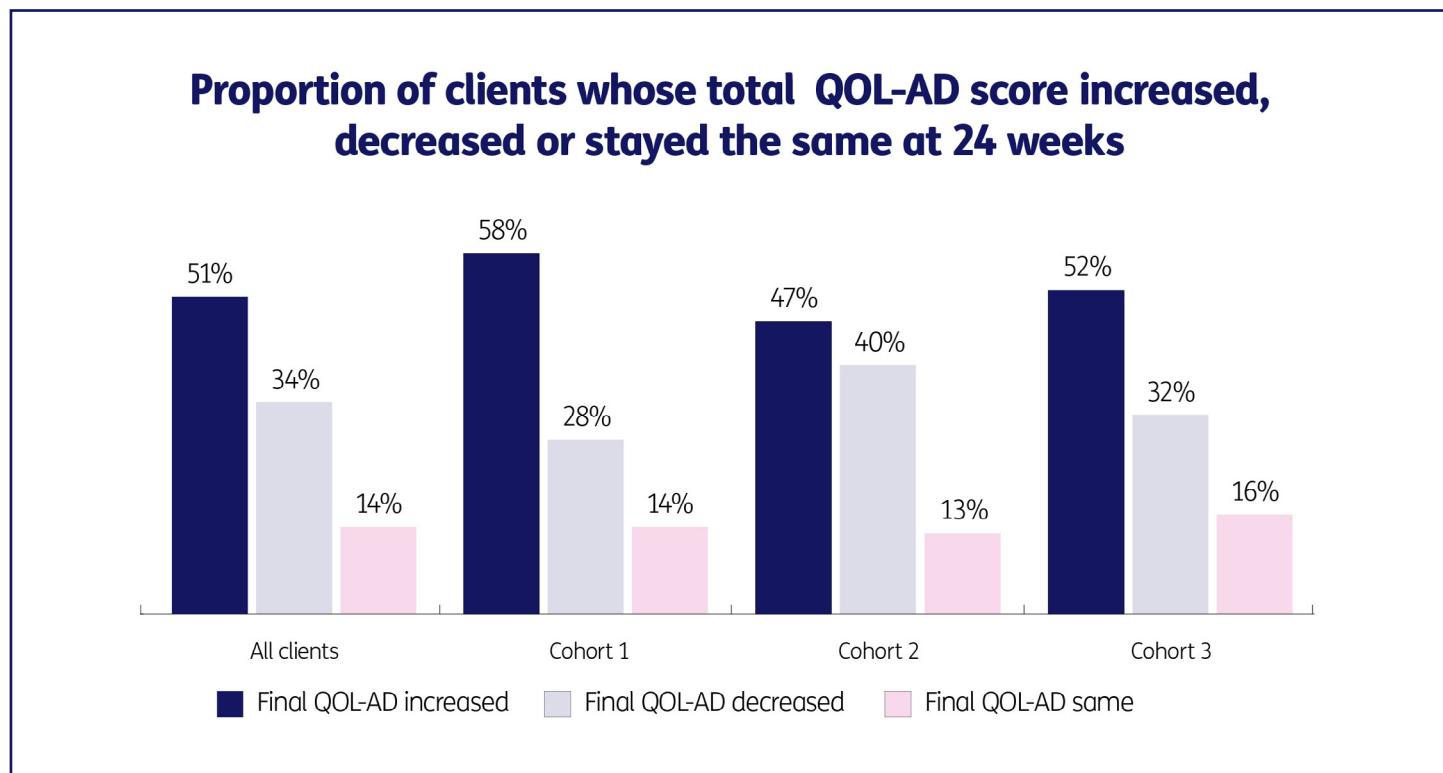Difference: +1.02 — Cohort 3

Legend: ■ Baseline ■ Final

All client base: 377; Cohort 1 base: 74; Cohort 2 base: 136; Cohort 3 base: 167

Figure 2: Changes in the mean total QOL-AD score from baseline to final data.

Please see Appendix 4 for data tables that show standard deviation, confidence intervals and statistical significance for data presented in the report.

While changes in mean total scores tended to be modest, individual clients' score changes varied greatly, as also noted by other studies.[14] Looking at the changes in individuals' total QOL-AD scores between baseline and 24-week follow-up, there was substantial variation across different clients. Some client scores increased at 24-weeks, others' scores decreased or stayed the same. The proportion of clients whose total QOL-AD scores increased was higher in cohorts 1 and 3 than in cohort 2, as shown in the table below:

Proportion of clients whose total QOL-AD score increased, decreased or stayed the same at 24 weeks

	All clients	Cohort 1	Cohort 2	Cohort 3
Final QOL-AD increased	51%	58%	47%	52%
Final QOL-AD decreased	34%	28%	40%	32%
Final QOL-AD same	14%	14%	13%	16%

All client base: 377; Cohort 1 base: 74; Cohort 2 base: 136; Cohort 3 base: 167

Figure 3: Proportion of participants whose total QOL-AD increased, decreased or stayed the same at the end of the programme.

As the data above shows, just over a half of all clients had increased QOL-AD scores, suggesting an improved quality of life. Looking at the extent of improvements in total QOL-AD scores, about a third of clients had final QOL-AD scores that were 3 points or more higher than at baseline. Going back to the discussion of the minimum significant difference, a difference of 3 and more is at the higher end of the range of changes that different scholars thought would be significant. In the view of Meeuwsen et al (2012), a difference of 3 in someone's total QOL-AD score is significant because it equals a move from Poor to Excellent in at least one area covered by QOL-AD.

208 carers also completed QOL-AD questionnaires to share their views on their loved one's wellbeing. There was a very small increase in carers' QOL-AD total mean score (+0.39), suggesting clients' quality of life improved very slightly at the end of the programme, from carers' point of view.[15] The smaller improvement in carers' scores may be due to the tendency that carers typically assess the quality of life of their family members living with dementia as lower than individuals themselves.[16]

In addition to looking at the changes in the total score at the group and individual level, it is instructive to consider any changes in client scores for individual QOL-AD questions. There are thirteen individual questions that make up the total QOL-AD score and looking at these individually highlights that there was a more positive impact in some areas than others. In particular, client scores improved for mood, how they feel about their memory and their ability to have fun, whereas scores for most other areas remained stable and unchanged. There were no areas of client lives where their scores suggested significant deterioration. The only score to worsen slightly concerned how clients felt about their family and relationships with family members. The charts below show the changes in scores that improved or worsened in the client sample.

Changes in how clients see their ability to have fun

Poor: 12% (Baseline), 8% (Final)
Fair: 30% (Baseline), 28% (Final)
Good: 46% (Baseline), 47% (Final)
Excellent: 13% (Baseline), 17% (Final)

Difference: 5% move from Poor and Fair to Good and Excellent

Baseline / Final

Changes in how clients feel about their memory

Poor: 23% (Baseline), 21% (Final)
Fair: 51% (Baseline), 46% (Final)
Good: 23% (Baseline), 31% (Final)
Excellent: 4% (Baseline), 2% (Final)

Difference: 7% move from Poor and Fair to Good

Baseline / Final

Changes in mood scores

Poor: 9% (Baseline), 8% (Final)
Fair: 36% (Baseline), 31% (Final)
Good: 47% (Baseline), 52% (Final)
Excellent: 8% (Baseline), 10% (Final)

Difference: 7% increase in Good and Excellent at the end

Baseline / Final

Changes in how clients feel about their family and family relationships

Poor: 7% (Baseline), 7% (Final)
Fair: 10% (Baseline), 9% (Final)
Good: 42% (Baseline), 48% (Final)
Excellent: 41% (Baseline), 36% (Final)

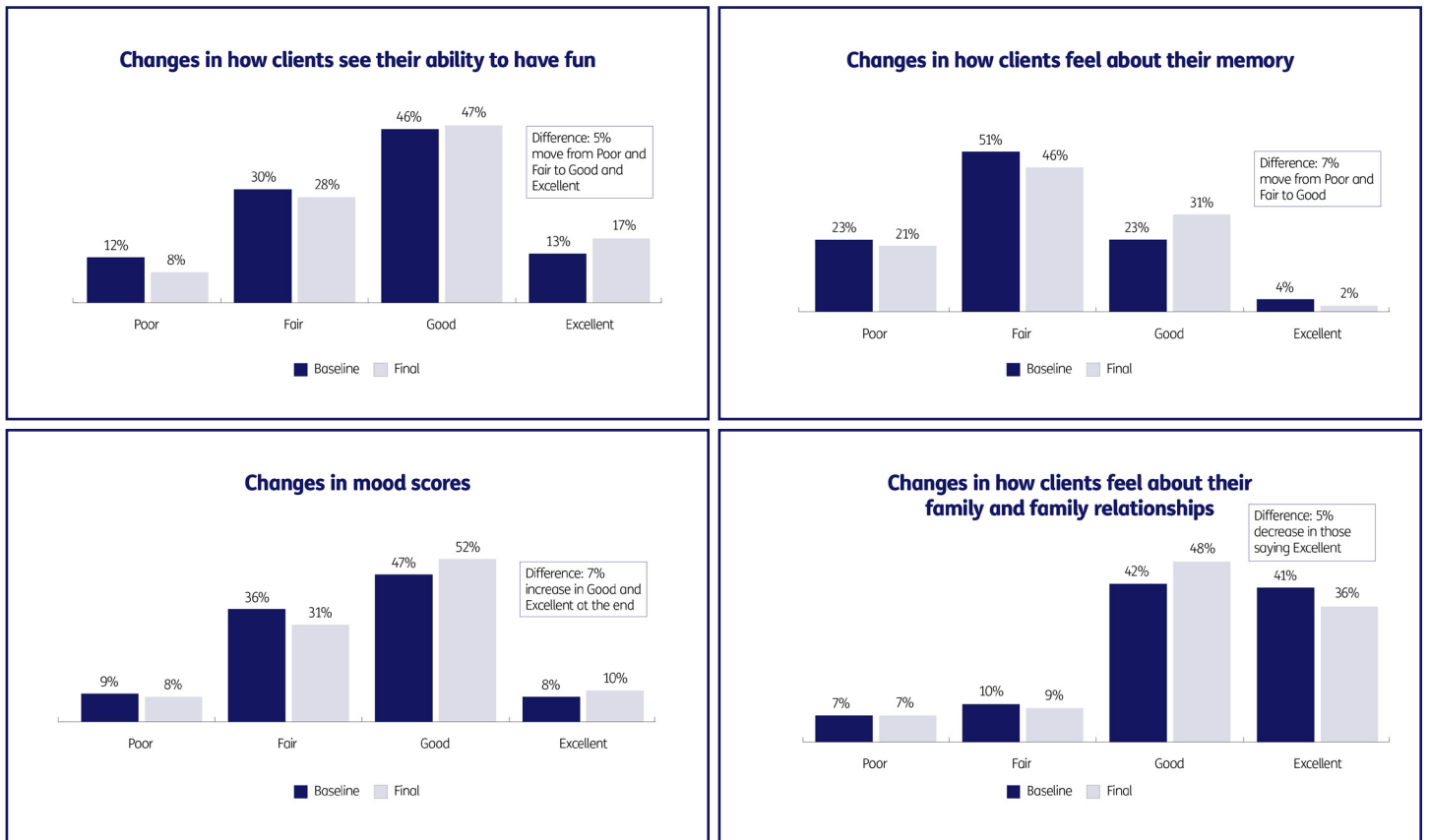Difference: 5% decrease in those saying Excellent

Baseline / Final

Figure 4: QOL-AD scores that improved or worsened over the duration of the programme.

Carers' QOL-AD scores for different areas of client lives largely remained the same and unchanged. There were two exceptions to this where carers' QOL-AD scores suggested small improvements in clients' lives from their point of view. When looking at the final carer QOL-AD scores for clients' mood, there was a 7% decrease in those saying that clients' mood was poor. In addition, 6% fewer carers said that clients' family relationships were poor or fair at the end than at the start.

Looking at different client groups, there are indications that some were more likely than others to see improvements in their quality of life, based on the difference between their baseline and final mean total QOL-AD scores. The following groups of clients had greater increases in their mean total QOL-AD scores, suggesting more improvement to their quality of life at the end of the programme:

- Face-to-face MCST clients.
- Younger clients, i.e. those aged under 75.
- Those with vascular dementia and those not diagnosed yet.
- Clients diagnosed less than one year ago.
- Those who did not already benefit from prior CST support.
- Those with lower-than-average baseline QOL-AD total scores.
- Clients whose baseline SMMSE scores indicated they had mild dementia.
- Clients whose final SMMSE scores suggested they had no cognitive impairment.

While these groups saw bigger improvement in their QOL-AD scores, this did not always mean their scores were higher than those of others. For example, those with lower-than-average baseline QOL-AD score improved more, however, their final QOL-AD scores were still significantly lower than for those whose baseline QOL-AD total scores were higher than average. Sometimes these groups started from a lower point and potentially saw more improvement because there was more scope to improve starting from a worse situation. Qualitative research may explain some of these improvements further. For example, clients, carers and staff sometimes commented that attending MCST helped those more recently diagnosed come to terms with their diagnosis and overcome the initial shock, depression and anxiety they felt following the diagnosis.

Differences based on gender, living arrangements and whether clients had prior contact with Age UK or not were extremely small, with broadly similar mean total QOL-AD scores in these different groups. The table below shows movement between baseline and final mean total QOL-AD scores for different client groups based on their demographic and other characteristics.

Client characteristics	Changes in mean total QOL-AD score		
	Baseline	**Final**	**Difference**
Delivery mode (No)			
Face-to-face (340)	34.59	35.44	+0.85
Online (35)	33.06	33.06	None
Gender (No)			
Male (156)	34.02	34.85	+0.83
Female (181)	34.62	35.33	+0.71
Age (No)			
Under 75 (101)	33.76	35.25	+1.49
Over 75 (229)	34.51	34.98	+0.47
Living arrangements (No)			
Living alone (110)	34.08	34.71	+0.63
Living with others (230)	34.44	35.28	+0.84
Type of dementia (No)			
Alzheimer (118)	35.59	36.08	+0.49
Vascular (45)	32.44	35.47	+3.03
Other types (99)	34.13	33.65	-0.48
Not diagnosed (60)	34.38	35.68	+1.3
Years since diagnosis (No)			
Less than 1 year (166)	33.48	34.73	+1.25
1-5 years (147)	35.24	35.31	+0.07
Had CST support previously or not (No)			
Yes (72)	35.06	34.64	-0.42
No (246)	34.1	35.22	+1.12
Had prior contact with Age UK or not (No)			
Yes (194)	33.7	34.41	+0.71
No (138)	35.07	35.95	+0.88
Baseline mean total QOL-AD score (No)			
Lower than average (153)	27.97	30.46	+2.49
Higher than average (204)	39.35	38.9	-0.49
Baseline SMMSE total score (No)			
Moderate dementia (127)	33.89	34.38	+0.49
Mild dementia (81)	34.78	36.19	+1.41
No impairment (125)	34.7	35.25	+0.55
Final SMMSE total score (No)			
Moderate dementia (90)	32.81	33.07	+0.26
Mild dementia (134)	35.41	35.88	+0.47
No impairment (104)	34.52	36.26	+1.74

Table 5: Changes in mean total QOL-AD scores for different participant groups

Qualitative findings

All clients, carers and staff included in the qualitative research felt the programme had a positive impact on clients' quality of life and wellbeing, whether they attended MCST face-to-face or online. Through discussions with them, the evaluation identified aspects in which the programme was felt to have improved clients' quality of life and wellbeing:

"A lot of the people that he used to know have passed away or he just doesn't see any more; so he is a lot more isolated than he's ever been, so getting out into a social setting where he can talk, communicate, have a laugh is a good thing." - Carer

"I want to tell somebody something but I can't find the words…. The people that I'm there with, they understand that so it's easier while I am there." - Client

"They look forward to it so much every week. They have formed friendships. Some of them have joined other groups we run during the week, some of them are getting together during the week." - Staff

"It feels like a safe community." - Client

- **Social connections and re-integration:** MCST groups were seen to have provided a safe and respectful space for clients to socialise, which all respondents felt impacted positively on their wellbeing and improved their quality of life. The groups were run in such a way that empowered clients to engage socially, without the fear of being misunderstood or embarrassed. This was different to their social interaction in many other situations, where they felt 'different' and that other people without dementia did not understand their situation. As a result, some commented they felt more connected to the world in their MCST groups. Clients also stressed they felt treated with respect and not patronised by staff, which was different to their experience of some other support services for people living with dementia.

  Many clients felt that their MCST group experience gave them more confidence to talk to people outside the group and be more social in general. Some clients explained their confidence improved as a result of forming new friendships and re-building their social skills. In some instances, this increased their motivation to engage socially. For example, a carer reported how their husband stopped interacting with other family members over the recent period, but that he started talking to them again following his MCST course. Staff made similar comments, for example, highlighting clients who joined other group activities or became more confident to go back to driving or travelling.

  Face-to-face sessions were felt to allow for more and better social interaction and more opportunities to socialise and make friends. For example, a staff respondent felt that interaction with and between clients was more difficult online. However, most clients and staff involved with online sessions still felt that clients built rapport with others in the group and got to know them and interact socially, only to a somewhat lesser extent. One client in an online MCST group reported that staff organised for clients to meet and go to a museum together. Perhaps, occasional get-togethers for online clients can be a way to overcome the perceived limitations around social contact online.

"One client's social life has changed, recently she went to see her friend in Liverpool, she is driving again, she is out and about so much more than she was before. She says coming to that group has helped her with that." - Staff

"A lack of confidence is a problem when you're conversing. The fact that he does it relatively happily in that situation gives confidence for other situations where he wouldn't possibly be as comfortable." - Carer

"They've made friends, as have their carers. Some now go to 'walking football' and 'Singing for the brain' together, and also to a walking group. One woman chose to go to the group on her 90th birthday to celebrate with her friends." - Staff

"While virtual groups are well attended and enjoyed, we found that things like building friendships and that real connection are stronger in face-to-face groups." - Staff

"You feel out of it most of the time and if they can lead you into a discussion, get your brain going as it were, you feel a lot better after and you go away satisfied and ready to start the next day." – Client

"I know they can't remember where they've been or what they've done, but their mood is so different when they come back, they're such a happy bunch and it will go into the next day as well." – Staff

"It's been a massive improvement in him, positive …. He's not crying any more, gets up in the morning, 'Oh what is it today'. He writes everything down in his diary, he's busier than me. So much more positive, just not depressed." – Carer

"I'm definitely happy when I'm here. Sometimes I am a little bit down at home because I'm sitting on my own. I'll try and not let that bother me." – Client

- **Improved mood:** Clients often talked about how much they enjoyed their MCST group sessions and having fun and laughter with others. Many stressed they always looked forward to coming to their group. Clients and carers alike appreciated the light-hearted nature of these sessions and thought that having something they could enjoy in life was very important for their mood and wellbeing.

  Carers noted that clients seemed cheerful after their MCST group session, for example, noting they were smiling or singing after sessions and were more engaged and talkative. Others commented how their loved ones seemed less anxious and negative after the sessions, or that it helped them feel less depressed. In most cases, carers thought these improvements lasted during the day of the session and sometimes 1-2 days after the session. The impact on clients' mood faded with time, but then they started again looking forward to their next session. Some carers therefore wished the sessions were more frequent to maintain the positive impact on clients.

  Staff echoed these comments, adding that the positive emotional impact stayed with clients the longest. Staff and some carers also emphasized the importance of improved mood in MCST clients for managing dementia, pointing out that depression can exacerbate cognitive decline.

"Being there and seeing people with greater challenges and further down the line with Alzheimer's… I welcome knowing more about it and understand it more through meeting people, rather than reading about it in a book. I can now see that actually it's not affecting any of the people there badly, they come out more joyously." – Client

"When someone comes up with something funny, we all have a good giggle which is a very good thing if you can have a giggle and a laugh while all this is going on. It just makes it a perfect meeting." – Client

"I've thoroughly enjoyed every part of it. There isn't a Friday I've felt out of place or not right. I've always enjoyed everything." – Client

"I quite look forward to it. Actually, it's my daughter's birthday today but her lunch has to wait until Grandma gets back from the group!" – Client

- **Living with dementia:** Meeting others in a similar situation through MCST made clients feel less alone, gave them a sense of belonging and enabled them to learn about how other people live with dementia. Clients reported how they shared experiences and tips on solutions to meeting various challenges posed by living with dementia. A staff respondent also noted how their MCST groups were often clients' first contact with any support so worked as a gateway to them asking and finding out about other support to assist them with living with dementia.

  Many clients also showed interest in observing and learning about different symptoms of dementia clients had in their group, commenting how this improved their understanding of dementia. For some, meeting other people living with dementia made them less upset and unhappy about their diagnosis: whether through feeling they were not alone in that or by appreciating the skills they still had.

  However, there were other experiences too, where attending the group sometimes exacerbated clients' unhappiness over their condition. This was rare as the research found only two clients with this experience, but their comments nevertheless highlight challenges involved in accepting their dementia diagnosis. In one case, the client felt anxious about their future after seeing people living with more advanced dementia than theirs. The client also felt somewhat out of place in the group, as they felt more capable than others, which they sometimes found frustrating. In another case, a client said that going to the group reminded them they had a problem, making them feel frustrated this was still the case despite attending MCST.

"It really motivates him; he would come here every day, every day he says, 'Am I going today then'? … I think it gives him the feeling of belonging somewhere, like being part of a club, it's like going to work, you're committed to it, you feel you should be going." - Carer

"You can be yourself and there is no pressure on you to remember anything, or act in a certain way or do a certain thing. It is nice that it exists." - Carer

"I think it's a great opportunity for you to do exactly that, be yourself, rather than have somebody saying, 'Are you sure you've got this, are you sure you've got that' … that's one thing that can happen, the person who wants to look after you will end up doing too many things and then you get used to it." - Carer

"Come away from it, I'm full of beans, I think I'm exactly the same as anybody else now." - Client

- **Self-esteem and motivation:** Clients frequently noted how the MCST programme helped them feel human again and more alive, more like the person they used to be. For example, some clients explained they enjoyed that the group made them feel 'ordinary', 'normal' and forget they had dementia. Other clients and carers also reported how helping others in the group made clients feel useful, making them feel better about themselves. Clients also explained that having their MCST community and activity gave them a sense of purpose and made them feel they had a life.

  Feeling better about themselves led to other positive changes in some cases, with clients more motivated to look after themselves or engage in other activities. For example, a client reported some positive lifestyle changes, such as having a healthier weight, and generally taking more care over their appearance. In another example, a client reported feeling more motivated and forward looking, tackling jobs around the house and holiday planning. Others talked about the programme giving them a reason to get up in the morning, get ready and go out of the house.

"It gives a direction to your life. Every week is made up of 7 days and it's nice to have something to break it up, that you can look forward to and enjoy and reflect back on afterwards. When you get home you think about it, what you said, maybe what you shouldn't have said, and that has got to be good for the brain." - Client

"It's good that they've got this little entity that's theirs; the ownership of being in their little group is really, really important; it's the only thing in the week where he's not with me!" - Carer

"As far as I'm concerned, if it wasn't for going to this place then I wouldn't live a life, to be quite honest. I have no car now, so I can't just get in the car and go anywhere anymore. I can't walk very far without having to sit down. It's difficult." - Client

"There is a noticeable improvement in his mood on group days and a sense of purpose. Having something in the diary is quite important. He is up and about and ready to go." - Carer

- **Routine and orientation:** Some carers further felt the programme gave clients routine and structure to their week, which they enjoyed. For example, one carer thought it made her husband more aware of the days of the week and more conscious of their weekly routines.
- **Independence:** Some carers and clients also highlighted the ways in which attending the programme bolstered the independence of older people living with dementia. They explained the course gave them something they did on their own – something that was 'theirs' – and sometimes also provided opportunity for independent travel to and from the course, which made them feel less dependent on others. Others commented on other ways in which the programme promotes independence, for example, through involving clients in activities such as tidying up.

"We also gently ask them to help (washing up, moving chairs etc) – often they're not allowed to do things at home. (Following the programme, some carried on with) gardening and helping around the house and the carers now giving them a simple task to do." - Staff

- **Digital inclusion:** Online MCST sessions delivered some additional benefits for clients that face-to-face sessions did not. Some clients got used to using digital technology and particular devices, which they then started using to communicate with family members and play games. One couple also started another online course, which they may not have done without this prior experience of online MCST.

"It's alright because I've actually spoken to my daughter in America on it (the tablet). It was exhilarating because I've not seen her for 3 years." - Client

"We have also gone to the History Group since we've started on the Zoom course." - Carer

"Mum and dad's generation are not used to Zoom and this has made it more comfortable. So, when we facetime relatives in India he is now more familiar with the sort of technology." - Carer

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SUMMARY CONCLUSION:

The evaluation found that the MCST programme achieved its objective from Outcome 1 to improve wellbeing of people living with mild to moderate dementia. Quantitative data showed that the mean total QOL-AD score for clients increased by 0.77 following the 24-week MCST intervention, suggesting an improvement in clients' quality of life. This is broadly in keeping with previous studies examining the impact of CST and MCST, which also found the intervention helped improve quality of life in people living with dementia. Qualitative research further found that clients, carers and staff felt that the improvements in terms of quality of life were significant. In particular, the areas where quantitative and qualitative data reflected each other potentially pointed to the drivers of this improvement. Specifically, both quantitative and qualitative research suggested improvements in terms of clients' mood, how they felt about their memory, and their ability to enjoy things and have fun. All of these were explicitly targeted by the MCST programme, suggesting that it contributed to these improvements.

4.2: IMPACT ON CLIENTS' COGNITIVE ABILITIES

As part of Outcome 1, the aim of the MCST programme was to improve cognitive abilities of people living with mild to moderate dementia. The programme has achieved this outcome based on both quantitative and qualitative findings which are discussed below.

Quantitative findings

The SMMSE questionnaire is widely used to assess cognitive impairment and as an outcome measure in clinical trials and evaluations of interventions seeking to positively impact cognition of people living with dementia. The questionnaire consists of 12 questions whose scores are added up to obtain the total SMMSE score, where the maximum score is 30. The total score indicates the level of impairment as follows:

Extent of cognitive impairment	SMMSE total scores
Potentially no impairment (but subjective memory problems)	25-30
Mild dementia	21-24
Moderate dementia	10-21
Severe dementia	0-9

Table 6: SMMSE total scores and stages of dementia

Research with people living with dementia suggests that, on average, SMMSE scores decline by 2-4 points annually (Clark, 1999), due to the progressive nature of the condition.

The SMMSE measure was used in previous research assessing the impact of CST and MCST on cognition in people living with dementia. The randomised control trial (RCT) of CST (Spector et al, 2003) found that it improved cognition of people with dementia. The mean MMSE score for the MCST treatment group improved by +0.9,

whereas it declined in the control group by -0.4. A later study on the effectiveness of MCST (Orrell et al, 2014) found that while MCST still impacted positively on quality of life of people of dementia (who previously attended CST), it did not improve their cognition further. The study authors considered that given the initial cognitive improvements resulting from CST, there may be limited potential for further improvements following MCST (in those who already had CST). At the same time, the mean MMSE score declined less in the MCST treatment group than in the control group, suggesting that MCST still had protecting impact to slow down the cognitive decline.

Looking at the SMMSE data for the Age UK's MCST programme, the evaluation suggested that clients' cognition levels largely remained stable over the period of the programme. The mean total SMMSE score for the sample of those whose SMMSE data was available (No = 349) was almost unchanged, moving extremely little from 21.85 at the start to 21.9 at the end. Given the findings mentioned above that SMMSE scores typically decline between 2 and 4 points per year, the stable mean score over a period of 24 weeks confirms the protective character of MCST in slowing down cognitive decline.

There were some variations between different cohorts in how much the mean total SMMSE score changed following the MCST programme. While it remained stable and saw very little change in cohorts 2 and 3, it improved more in cohort 1:
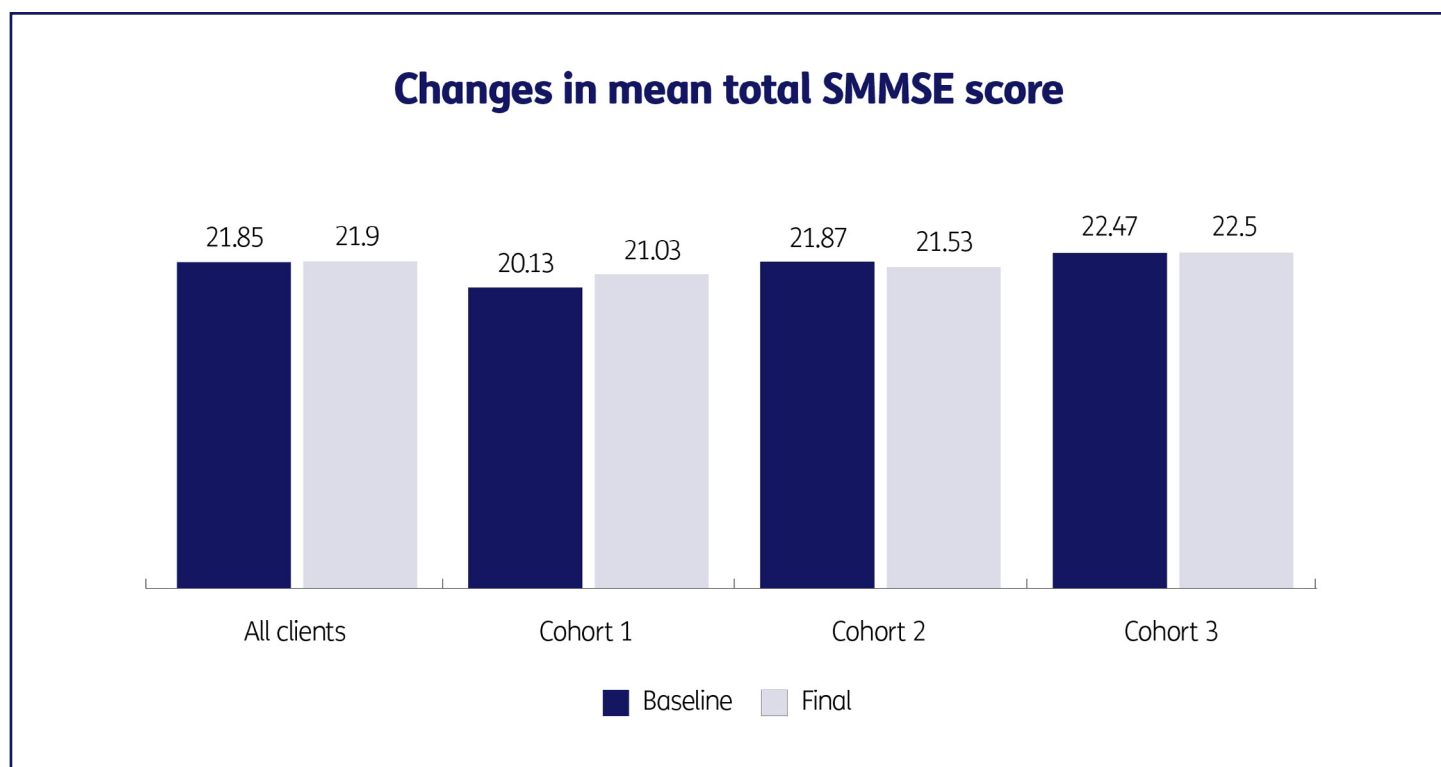
Base: All clients (349); Cohort 1 (61); Cohort 2 (123); Cohort 3 (165)

Figure 5: Changes in the mean total SMMSE score

While the mean total SMMSE score changed little in this sample of MCST clients, there was significantly more change when looking at the proportion of those whose total SMMSE scores suggested different stages of dementia. The most noticeable change in this respect was an increase in the proportion of clients whose final total SMMSE scores suggested they had mild dementia. At the start of the programme, 24% of clients had scores that indicated mild dementia compared to 39% at the end of the programme. This increase in scores suggesting mild dementia has largely come from changes in the final scores of two other groups of clients: those whose baseline scores indicated moderate dementia and those identified as having no impairment at the start.

- There was a 10% shift from moderate cognitive impairment to mild cognitive impairment, suggesting that some clients did have an improved cognitive functioning at the end of their MCST programme;
- There was also a small decline with 6% of clients moving from scores indicating potential no impairment at the start to scores suggesting mild dementia at the end.

The chart below shows the changes from baseline to final total SMMSE scores and the levels of dementia they indicate.

Changes in mean domain C-DEMQOL scores

	Personal needs	Carer wellbeing	Carer role/ patient-carer relationship	Confidence in the future	Feeling supported
Difference	-0.41	-0.27	**-1.01**	-0.28	-0.25
Baseline	18.08	17.6	21.84	17.5	19.62
Final	17.67	17.33	20.83	17.22	19.37
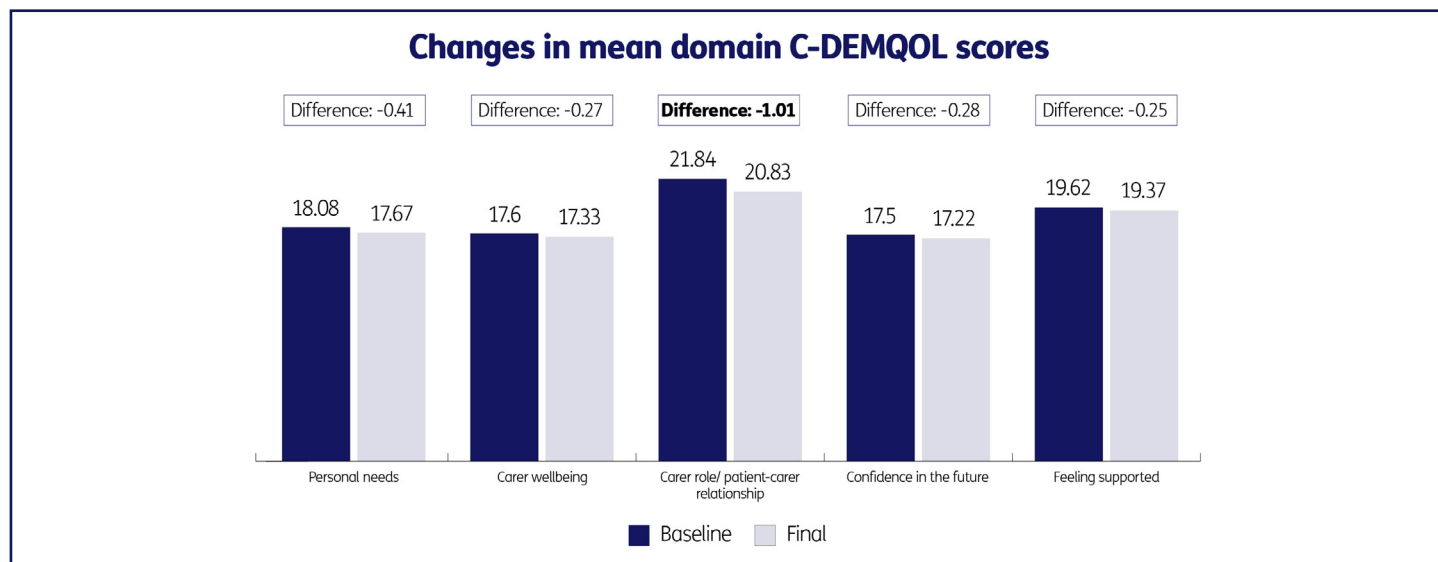
Base: 349

Figure 6: Changes in proportions of participants at different levels of dementia based on their SMMSE score

There was even more change in SMMSE total scores at the level of individual clients. A significant proportion of those whose scores indicated moderate dementia at the start improved over the duration of the programme – 38% of these clients had increased total scores at the end, indicating improved cognition and movement towards mild level of dementia or no cognitive impairment. However, clients whose SMMSE total score suggested no impairment at the start were more likely to experience decline than other groups – 35% of these clients had lower scores at the end (28% moved to mild dementia, 6% to moderate and 1% to severe).

Analysis of the improvement in SMMSE scores by demographic and other client characteristics has found variable results – with some factors such as gender and age not being associated with differences in cognitive improvement, and others potentially linked to small differences in client outcomes. Certain groups of clients were more likely to see more improvement in their mean SMMSE total scores at the end, as follows:

- **Those attending MCST online:** the final mean total SMMSE score for online MCST clients increased by 1.03 points, whereas the score for face-to-face clients remained almost unchanged (-0.07).[17]

- **Those with vascular dementia:** Clients with vascular dementia had a higher mean total SMMSE score at the end, which increased by 0.72. This wasn't the case with other groups: scores for clients with Alzheimer and other types of dementia changed very little (-0.17 and +0.20 respectively), whereas the mean total score for those not diagnosed yet declined slightly (-0.82).

- **Those whose baseline SMMSE scores indicated moderate dementia:** Those with SMMSE scores indicating moderate dementia at the outset improved most – their mean total SMMSE score at the end increased by 1.08 points. Those whose SMMSE scores at the start suggested no cognitive impairment declined most – their final score decreased by 1.27 points. The mean total SMMSE score for those with mild dementia at the start remained almost the same.

- **Those whose final SMMSE scores suggested mild dementia or no cognitive impairment:** Clients whose final scores suggested they had mild dementia or no impairment had more increased scores compared to the start, reflecting the cognitive improvement they experienced during the programme. The mean SMMSE score for those with mild dementia at the end increased by 0.73 compared to the start, whereas the score for those who registered no impairment at the end increased by 1.7. Conversely, those whose final SMMSE scores suggested they had moderate dementia declined by 1.84 points compared to their baseline mean total SMMSE score.

- **Those whose final QOL-AD total scores were higher than average:** Those whose final total QOL-AD scores were higher than average also showed more improvement in their final SMMSE scores, than those whose final QOL-AD scores were lower than average. The first group had the final mean total SMMSE score that was 0.76 higher than at the start, whereas the SMMSE mean total score declined for the second group by 0.63 at the end.

Qualitative findings

Most clients, carers and staff believed that clients got beneficial cognitive stimulation from the sessions and that this helped improve certain aspects of cognition for some. However, views were more mixed on whether cognitive stimulation from MCST impacted clients' memory.

- **Cognitive stimulation:** Clients, carers, and staff agreed with a general idea that MCST sessions were cognitively beneficial for clients, as they engaged them to actively participate in various activities and social interaction. Staff stressed the sessions allowed clients to use their cognitive function with the aim of improving and maintaining their cognitive abilities. This feedback was the same whether clients attended face-to-face or online MCST.

  Clients and carers also pointed out the sessions made clients focus, remember things from the past, talk to others, and solve problems. All this was felt to be useful for making clients use their cognitive skills and be more engaged mentally and socially. For example, some carers commented how clients seemed more alert, interested in things and communicative following their MCST group, as well as less confused.

"It improves (your mind), whether it lasts very long is another matter but you come out of there on top of the world … you get your confidence back, I feel like I can handle anything for a short period of time which is what it's all about really." - Client

"You can see and feel and hear that people are brightening up and connecting up thoughts and observations so that's really nice. I'm only now paying attention to how other people are, coming out of my shell." - Client

"When my mum comes home you can see she can do the puzzles in the local paper, she can tell us everything that she's done while she's been there so it's definitely helping her." - Carer

"Sometimes he can be quite quiet, whereas he's chatty when he comes back and he's a bit more aware of things." - Carer

Carers' views varied on how long these benefits lasted. Most agreed they stayed with clients for the rest of the day of their MCST group, sometimes lasting for another day. Some carers also pointed how long positive impact lasted varied depending on other things going on and there was no 'set time'.

"I think improvements in mood makes a difference to the other side as well. When you are having a low day your symptoms on the other side get worse. If you are happy and you are settled everything else improves with it as well." - Carer

"It has also stimulated brain to the extent that is making him think about things and talk about things that he wouldn't otherwise." - Carer

- **Improved confidence in using cognitive skills:** Clients' comments also suggested that taking part in MCST activities raised their confidence in using their cognitive and other skills. Clients, carers and staff highlighted different ways in which MCST sessions helped with this:
  - Solving tasks made clients feel pride and gave them a sense of achievement;
  - Remembering things from the past made them feel they were still parts of their memory they could use and made clients feel better about their memory;
  - Varied activities helped clients identify skills they could still use and remember those they once learned in the past, for example, a client was thrilled they could still remember how to do water colouring;
  - Feeling safe and supported encouraged clients to attempt things they found more difficult, for example, speaking for those who struggled to find words;
  - Sharing experiences of dementia with others provided reminders of useful coping mechanisms, for example, writing things down;
  - Dealing with tasks themselves, rather than with the help of carers, promoted a sense of independence in clients;
  - In some cases, clients carried on doing certain activities at home too, extending cognitive stimulation;
  - In one carer's view, mood improvements also impacted positively on cognition too by reducing symptoms of dementia.

"We've got a gentleman who really struggles with his word-finding and he says coming in an environment where people are so understanding, he feels like he's in a safe space to take his time and he says that's really helped him with his confidence and cognitive abilities and that's improved." - Staff

"Because we do quizzes, a lot of them will say now in their own homes they'll watch the 1% club on a Saturday, so they'll stretch and test their minds more outside of the group." - Staff

In addition, staff observed various improvements within the sessions: some clients' engagement and participation in activities improved over time, they became quicker at certain tasks; seemed more aware of dates and days of the week; and surprised themselves by things they were able to do. Other staff pointed out, however, that clients varied greatly and so did the impact of sessions, with some staying at the same level and slowing progression of dementia, some improving, and others declining.

"I think because we had a structure every week, the questions like what's the weather like today, what's the date, they might be more inclined to think about those things, and ask themselves that. Two in particular were very keen to try anything and really did try their best to come up with ideas and thoughts and opinions. So, encouraging them to think about and question things is good." - Staff

"We had clients who previously did not know the name of the group and who now recall that; one individual who now has really good recall of the sessions and didn't previously; one client who now confidently reads out the paper and who wasn't able to do that in the earlier sessions." - Staff

- **Memory – clients' and carers' views:** Views from clients and carers were mixed on whether they noticed any positive impact in terms of clients' memory. Clients were more likely than carers to think they have noticed some improvements. For example, they appreciated that MCST sessions helped them remember things from the past and some cited this as an example of a positive impact on their memory. Some also noted they could remember the names of people in the group and felt the sessions tested their memory and made them use it, which they believed had positive impact.

  Carers' experiences and views in this respect varied. Many thought clients' short-term memory was the same or worse, commenting how clients could not tell them what activities they did in the groups. Others reported their loved ones remembered some activities for a short time after the group session or remembered some of the people from their group. For example, those carers reported how clients sometimes carried on talking to them about group activities, which helped stimulate conversation with carers and other people.

  A few carers also highlighted a challenge in judging how beneficial MCST sessions were for their parents or partners living with dementia. They felt this was very difficult to tell given they could not know what their loved ones would be like without this intervention. Some also noted it can be difficult to judge improvements in terms of memory as it could vary on a day-to-day basis.

"We don't have a comparison for whether it has improved cognition because we haven't tried it without. Because you have been going for some time and there is an expected decline, I don't know where we sit against that curve. It's hard to say whether it has made a difference, but I'd like to think so." - Carer

"It's really hard to say about memory because one of the things that I'm very aware of with [clients name] is that his memory varies hugely, not just from day to day but hour to hour so that's a tricky one to identify whether something's having a positive effect. I imagine it would but it's difficult to say." - Carer

"It tests your memory. I think that's probably the biggest gain that we get. It does help my memory a good bit I would say." - Client

"I can remember everyone's names in the group." - Client

- **Memory – views from staff:** Staff cited examples where they thought MCST helped maintain or improve certain cognitive skills and memory in clients. For example, some mentioned how some clients remembered other clients, greeted them, or remembered their names and some details about them. Other staff respondents commented how some clients became more confident with money, remembered more memories as time passed, or recognised the structure of sessions over time, e.g. orientation. At the same time, similarly to carers, some staff felt it was very difficult for them judge the extent to which the sessions had positive impact on clients' cognition and memory.

Finally, qualitative research may help understand some of the quantitative findings concerning the impact of the programme on cognitive abilities of people living with mild to moderate dementia. For example, it may shed some light on different outcomes in different client groups:

- As mentioned, clients in cohort 1 (Oct 2021-Apr 2022) saw bigger improvements than those in cohort 2 (Apr 2022-Jan 2023) and cohort 3 (Jan-Sep 2023). Qualitative research suggests that the positive impact of MCST in cohort 1 may have been amplified by the benefits of social re-integration following the lockdowns and isolation during the Covid-19 pandemic. For most clients in cohort 1, this was the first opportunity to re-connect and engage socially during the Covid-19 pandemic, enabling them to use some of their cognitive skills which may have deteriorated in the conditions of social isolation.

- As also explained earlier, those whose SMMSE scores suggested moderate dementia at the outset saw the biggest cognitive improvements, with 38% moving to scores associated with mild dementia or potentially no cognitive impairment. This finding is better understood in the context of qualitative research which showed that the programme helped clients re-discover some of the cognitive skills they lost through improving their confidence and giving them a chance to use them in a safe place. The evaluation therefore suggests that MCST has the potential to push some of the people with moderate dementia towards higher cognitive skills and less impairment.

More generally, these cognitive improvements should be further considered against the backdrop of the relationship between cognition, mood and quality of life. The quantitative data showed that clients with higher-than-average QOL-AD scores at the end of the programme also experienced bigger cognitive improvements. Similarly, those whose final SMMSE scores indicated potentially no impairment also saw bigger improvements in terms of their final QOL-AD scores. These quantitative findings were echoed in comments from carers and staff who felt that improved mood and quality of life were instrumental in making clients more confident, engaged and motivated to use and maintain their cognitive skills.

SUMMARY CONCLUSION:

The evaluation found that the MCST programme achieved its objective from Outcome 1 to improve cognitive abilities of people living with mild to moderate dementia. The mean total SMMSE score for the MCST client sample group remained stable over the period of 24 weeks, suggesting the intervention helped protect clients' cognitive abilities and slow down their decline. The SMMSE data further suggested that the programme helped improve cognitive abilities of some clients; most notably, 38% of clients whose SMMSE scores suggested they had moderate dementia at the start of the programme improved as their final scores were indicating mild dementia.

These findings were also supported by qualitative research as clients, carers and staff highlighted various improvements in clients' cognition, for example, being more alert, engaged and focused, less confused, more communicative, getting quicker at certain tasks, being more aware of time, and having more confidence to do certain things for themselves. Carers and staff were less certain that the intervention improved clients' memory, although some did see improvements in this respect too.

The findings on improvements to both clients' cognition (and quality of life) highlight some potentially helpful learnings for promoting MCST with people living with dementia and their carers. Firstly, the idea of using MCST to slow down cognitive cognition is likely to be appealing to clients and carers. Secondly, too much focus on memory at the expense of a range of other cognitive abilities may not be helpful. The evaluation suggests that carers in particular find it harder to see improvements in terms of memory. At the same time, both clients and carers could see improvements in other cognitive abilities, which they valued greatly. Emphasizing improvements in a range of cognitive abilities may be helpful in making the benefits seem more credible to carers. Thirdly, the positive impact on clients' mood, wellbeing and quality of life is also likely to be highly appreciated, so should also be promoted to engage people living with dementia and carers with the service.

4.3: IMPACT ON CARERS

The programme's second outcome was to improve wellbeing of carers of people living with mild to moderate dementia. The evaluation found that the programme achieved this outcome to some extent through providing respite, peer support and in some cases also other support. However, it also suggested that carers' overall quality of life deteriorated slightly over time due to the demands of caring.

Quantitative findings

The C-DEMQOL questionnaire consists of 30 questions which are divided into 5 domains, each focusing on a particular factor affecting carers' quality of life. The five domains include: Personal needs; Carer wellbeing; Carer role / patient-carer relationship; Confidence in future; and Feeling supported. The questionnaire provides a total score and domain scores, indicating an overall quality of life and carers' views on their situation in particular domains. The maximum total score is 150 and the minimum 30; higher scores indicate better quality of life. To understand any changes in carers' quality of life, baseline and final total and domain C-DEMQOL scores would be compared.[18]

C-DEMQOL data was collected from carers of MCST clients in cohorts 2 and 3 to assess any changes in their quality of life.[19] The data suggested some worsening of the overall quality of life in the carers' sample (No = 179), as their mean total C-DEMQOL score dropped by 2 points, from 94.63 to 92.63. A closer look at individual C-DEMQOL questions and domains found that this decrease in the total score over time was largely driven by the decline in one particular area of carers' life – the domain of the carer role and patient-carer relationship. While scores for other questions and domains declined very slightly or hadn't changed much, they declined more significantly in this domain. The changes between baseline and final mean domain C-DEMQOL scores are shown in the chart below.

Changes in mean domain C-DEMQOL scores

| Difference: -0.41 | Difference: -0.27 | **Difference: -1.01** | Difference: -0.28 | Difference: -0.25 |

| 18.08 | 17.67 | 17.6 | 17.33 | 21.84 | 20.83 | 17.5 | 17.22 | 19.62 | 19.37 |

Personal needs · Carer wellbeing · Carer role/ patient-carer relationship · Confidence in the future · Feeling supported
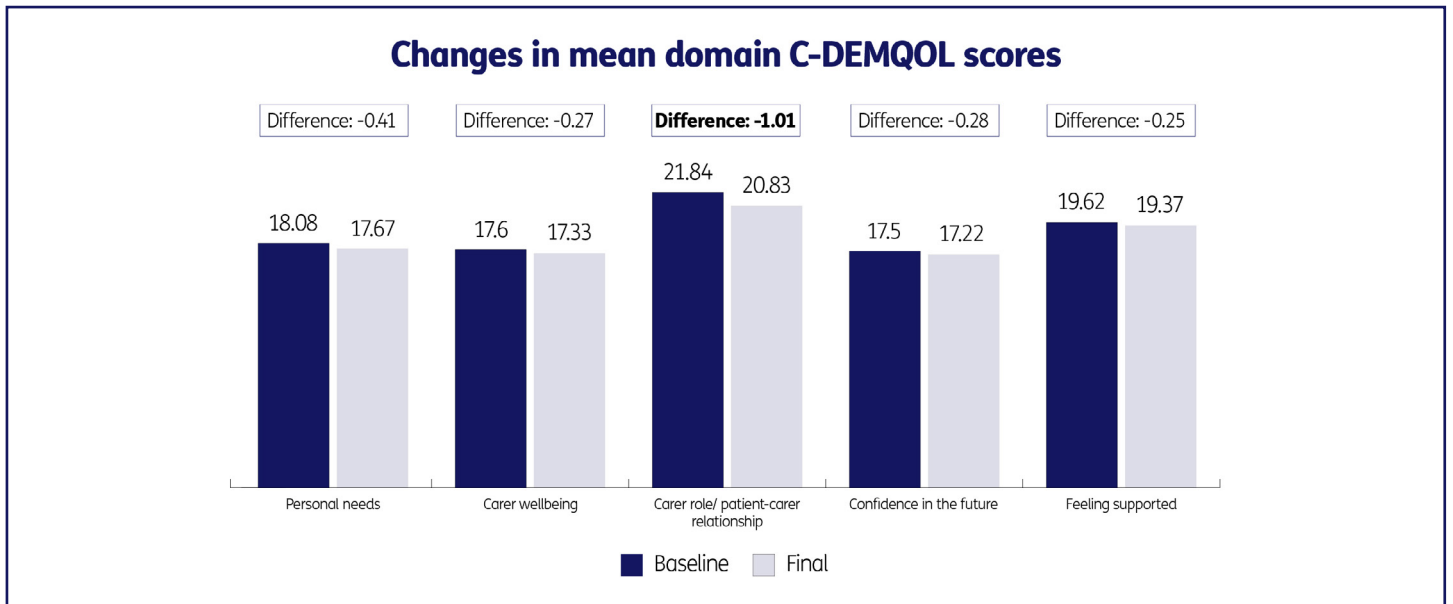
■ Baseline   ■ Final

Base: 179 (cohorts 2-3)

Figure 7: Changes in mean domain scores between baseline and final data

Looking at the individual questions, most scores have changed very little between baseline and final questionnaires: the scores for 21 out of 30 questions had changed less than 0.1 points. Of the remaining 9 questions where the changes had been higher than 0.1 points, 5 questions were in the domain concerned with the carer role and their relationship for the person they care for. The data for this domain suggests small but persistent decline in this area:

Carer role / patient–carer relationship domain (No)	Difference between baseline and final data
Q13. Coping with demands of caring (No = 179)	• 0.34 drop in mean score for this question in final data (3.7 to 3.36), which is the biggest decrease of all C-DEMQOL questions; • 15% fewer carers thought they coped quite or very well at follow-up than at baseline; • 9% more carers thought they coped quite or very poorly 24 weeks later.
Q14. Feeling resentful about their role as a carer for a person with dementia (No = 175)	• 0.12 decrease in mean final score for this question (2.22 to 2.1) • 9% fewer carers said they felt not at all or a little resentful when thinking of their present role as a carer for a person with dementia
Q16. Relationship with the person they care for in the past 4 weeks (No = 178)	• 0.14 decrease in the mean final score for this question (2.93 to 2.79) • 8% fewer carers thought their relationship with the person they care for has been quite or very good in the past 4 weeks
Q.17. Feeling appreciated by the person they care for (No = 179)	• 0.18 decrease in the mean final score (3.77 to 3.59) • 7% fewer carers felt appreciated by the person they cared for almost always or often; • 7% more carers said they felt appreciated by the person they cared for once in a while or never.
Q18. Feeling frustration towards the person they care for (No = 174)	• 0.18 decrease in the mean final score (3.63 to 3.45) • 12% fewer carers said they felt frustration towards the person they cared for none of the time or a little of the time

Table 7: Changes in the scores for C-DEMQOL Carer role / patient-carer relationship domain

Outside the carer role domain, several other questions showed a small deterioration in carers' feelings about their situation:

• **How much energy caring is taking:** there was a drop of 0.13 in the mean final score for this question, suggesting a small worsening on the level of this sample;
• **Emotional demands of caring:** 7% more carers felt that the emotional demands caring placed on them were quite or very heavy;
• **Feelings about meeting care needs in the future:** 8% more carers said they had significant worries or worried a lot about this.
• **Support from friends and family:** the proportion of those who felt they had little or no support from friends and family increased, by 9% and 5% respectively;

Qualitative findings

While quantitative findings suggested a small decline in the overall quality of life of carers and the relationship between the carer and the person they cared for, qualitative research found carers saw the benefits in respite and support from the MCST programme:

- **Respite:** Most carers of clients who attended face-to-face sessions felt this allowed them some respite, as it gave them 1.5-2 hours to spend on things they needed to do or enjoyed. Carers reported how they used this time for socialising and chores, or just as time they could spend on their own and recuperate mentally.

  In a couple of cases, MCST was provided as part of a day service, providing a whole day of respite to carers. Staff in those local Network Partners felt that two hours would be too short to provide respite; however, most carers highly valued even that amount of respite time.

  Where MCST sessions were shorter (for example, one hour long), carers felt this was not enough time to allow them respite. Carers who worked full time sometimes also found it difficult to drive their partner or parent to MCST sessions, which made them less likely to feel they had a respite.

  Online MCST sessions were generally found to provide less respite for carers, as they typically had to support clients to attend these sessions online. Some carers still used that time to do jobs around the house, which was beneficial. Where carers were partners, some joined in activities and enjoyed having something to do together with their partner. This was sometimes more difficult where carers were children of clients or other family members who did not live with them, as this required a separate visit for them to assist with technology. In addition, a staff respondent suggested online MCST sometimes increased carers' work, where it was their responsibility to help the client join the online meeting.

"Just the sheer fact of having that space for an hour and a half, today I just went home, sometimes I go to the market, I'm not thinking about what we are doing next, it's my space so it's important in that way. It just makes me feel I can carry on sort of thing." – Carer

"Well, it's good because… this sounds dreadful … but when he's at the class I can do anything I want. I'm in the garden or go for a walk. I've got time for myself." – Carer

- **Carer support and information:** Carers of clients who attended face-to-face sessions sometimes also felt they benefited from meeting other carers and being able to share information and informal support. Other carers in the same situation preferred to have time off and a couple felt they would find it depressing talking about dementia to other carers.

  In most cases, carers met each other informally at drop off and pick up times, but a few partners also organised weekly, separate carer support groups which ran during MCST sessions. In these groups, carers could share their experiences and advice or hear talks from guest speakers. Carers who attended these groups felt they benefitted from them greatly. Attending their carer group made them feel less alone, helped them learn about living with dementia and accessing other support, and form friendships and peer-to-peer support network (for example, setting up a carer WhatsApp group).

  Carers welcomed being given information about individual MCST sessions, the overall MCST approach, or access to support services. In particular, carers liked knowing what themes were covered in individual MCST sessions, so they could talk about this with their partner or parent after the session. Where this information was missing, carers wished it was provided. Many also appreciated getting some feedback from MCST staff on whether their loved ones engaged with the sessions and participated in activities. In some cases, carers were interested in slightly more detailed feedback on how the person they cared for managed different activities in MCST sessions to help them understand the level of their dementia.

  A few carers were also keen for staff to support them to learn to use MCST activities themselves: as mentioned, one MCST group hoped to continue and to be led by one of the carers. However, interest in carrying out MCST activities on their own was not universal, partly because some carers felt they would not be able to do this and also because they thought their family members living with dementia would be less likely to do these activities with them, at home.

"It's very useful because I'm still very new to this. I'm getting a heads up about what I need to prepare for so that my dad gets the best life and assistance that he needs to cope with the changes that will follow. Just having that opportunity to be able to talk openly with people who are in the same situation is really useful." – Carer

"It makes you feel that you are not alone and sharing something with others who are also devastated by this." – Carer

- **Mood and wellbeing:** Most carers thought the MCST programme made a positive difference to their mood and wellbeing too:
  - Carers felt satisfied their loved ones were being supported at MCST sessions and were reassured they were safe and looked after there. Some commented how they felt happier that their loved ones were happier.
  - Some carers further felt that because clients were in a better mood, that made it easier to care for them. MCST group experience also gave carers and clients something to talk about.
  - Finally, one carer said that MCST experience gave them more confidence to look for other activities for their mother, as they now thought she could do more.

"It's something where I know you are safe and they will deal with problems. Having that confidence that someone is looking after you, I feel I can go away and do other things safe in the knowledge that you are completely safe." – Carer

"Since he's been doing all of the classes including that one (MCST), he's better in himself. So, if he's alright, I'm alright. It can be very draining, so I love it when he goes to his classes." – Carer

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SUMMARY CONCLUSION:

The evaluation suggested that the MCST programme achieved its Outcome 2 to improve wellbeing of carers of people living with mild to moderate dementia to some extent, but that carers' quality of life still deteriorated over time due to the demands of caring. Most carers consulted through qualitative research felt the programme gave them some respite and made them feel better knowing their loved ones were supported in a safe place. In a small number of cases where additional carer support was provided, carers also felt they benefitted from better understanding of dementia and services they could access, as well as emotional support. At the same time, quantitative data suggested small worsening in carers' overall quality of life, how well they felt they coped with the demands of caring, their relationship with the person they cared for, and support from family and friends.

These opposite findings suggest that the programme conferred some benefits to the carers but that in most cases they were not significant enough to affect the carer situation so that their quality of life was improved. That may not be a surprise given the demands of caring for people living with dementia and that most partners in the programme did not specifically target carers with additional support.

The findings above raise questions about the extent to which the MCST programme could address the factors potentially dragging carers' quality of life down. In future, the programme could provide targeted carer groups alongside MCST client groups to support those interested to engage in this way. Such groups could potentially help carers cope better with the demands of caring through helping them access any other available support and providing emotional and psychological support. The programme, however, has no control over some other factors impacting carers' quality of life, but carer peer groups could potentially provide carers with a new support network.

4.4: IMPACT ON STAFF KNOWLEDGE, SKILLS AND CONFIDENCE

The evaluation found that the MCST programme achieved its outcome 3 to provide staff with the knowledge, skills and confidence needed to deliver MCST.

All staff respondents agreed that the training and experience of running MCST groups gave them the knowledge, skills and confidence to deliver MCST sessions. Staff also felt that running the MCST groups was rewarding. Specific benefits however varied depending on staff background and whether they had previous knowledge and experience of working with people living with dementia or running group sessions.

- **Benefits for staff with previous background in dementia:** These respondents still felt they improved their knowledge and skills. Some thought that their training and MCST experience provided them with new ideas for activities or materials when working with people living with dementia. Others said they found it refreshing that MCST allowed more focus on people with mild dementia or that they expanded their understanding of dementia in other ways. For others yet, MCST provided new experience and skills of running group sessions, improving their confidence to deliver activities to groups.

"I've worked on the dementia ward in the hospital for 4 years but doing that (Train the trainer) course taught me so much about living with the condition. (...) Mostly how behaviours had come around. There were a couple of case studies, for example, a man that kept pulling off his pyjamas – you just assume it's because he has dementia, but the study showed that he was a very proud man that used to wear very smart clothes and a tie all the time and it was his way of saying he didn't feel comfortable in old pyjamas. It makes you question why they are behaving in a certain way, what is the background (reason) that has caused it." – Staff

"There were some things that I already knew but I'm always wanting to learn more about dementia. I used to work with those with mid-long stage dementia so I've found it interesting working with people right at the beginning of their journey." – Staff

"It's given us quite a lot of knowledge on how people's progression of dementia can be. Because you are working with people over time, you can sense it a lot quicker. It is absolutely heartbreaking but at the same time I find it so rewarding to gain the knowledge. (We) should remember that dementia doesn't define the person, they've had a whole life before the dementia came along." – Staff

A few respondents also noted some areas where they felt less confident or where guidance provided to staff could be improved:

- A couple of staff respondents pointed out that the name of MCST suggested they were therapists, which they thought implied more training and skill. This made them feel uneasy about presenting themselves as therapists and expectations this may create in terms of what they can deliver and achieve. Conversely, a few staff emphasized the appeal of MCST as a non-pharmacological therapy.
- As mentioned previously, some staff also highlighted areas they thought should be addressed in staff training:
  - How to adapt MCST for online sessions.
  - How to adapt MCST to individual group interests / how flexible can the MCST programme be.
  - How to make MCST programme more culturally diverse.
  - What to do if clients become anxious or angry.
  - More interactive elements where they could practise what they will be doing in MCST sessions, as well as considering whether observing sessions could be part of the training where possible.
  - Easy ways to share and access materials and resources across different partners, where possible.

Staff across the board also talked about the satisfaction that running MCST groups gave them and seeing how they benefited people living with dementia. At the same time, there were some circumstances where this work was recognised as potentially being emotionally intensive for staff. This was particular to situations where staff ran multiple MCST groups so had a greater number of clients they supported. Where staff became aware that clients required further support and help, they felt a duty to follow this up and help out. To help support staff in this situation, regular debriefs were introduced where staff reviewed any such need for follow-up action and supported each other emotionally and with any decisions and actions involved.

SUMMARY CONCLUSION:

The MCST programme achieved outcome 3 as staff felt it improved their knowledge, skills and confidence to deliver MCST interventions. They highlighted the key areas where they felt their knowledge and skills improved: working with people living with mild dementia; ideas for materials and activities for people living with dementia; skills in running group sessions; and broader understanding of dementia and people living with dementia. Staff also shared some suggestions for improving training, guidance and resources for MCST staff, most notably, by making it more practical and interactive and providing guidance on how to adapt the programme.

5: How is MCST different from other dementia support services?

The question of how MCST differed from other dementia support services was discussed with MCST clients, their carers and Age UK staff delivering MCST and involved in other dementia support services. It was also explored in six expert interviews with diverse professionals with knowledge of dementia support services. Across these different groups, respondents compared MCST to a range of locally available services they were familiar with, including CST, day centres for people living with dementia, other activity-based programmes for people living with dementia (for example, singing, arts) and memory cafes.

MCST and CST were seen to be the same service by experts and some staff, participants and carers, as they followed the same approach, with some differences in terms of duration of the programme and frequency of sessions. Another difference was that CST was offered first, following the diagnosis, and then followed by MCST, where appropriate and where both of these services were available. CST and MCST, on the other hand, were felt to be different to other dementia services listed above and to have some unique features and benefits, as follows:

- **Therapeutic aims:** The first way in which they were seen to be different was their explicit and clear focus on improving and maintaining cognitive skills in people living with dementia. There was a perception from clients, carers and staff that MCST sessions were more work-like, in making clients think and requiring more intense concentration than, for example, social gatherings. In addition, MCST programme and activities were seen to be more structured, challenging and intricate than what clients and carers observed elsewhere. Small groups were seen as critical to providing bigger cognitive benefits by ensuring that everyone was engaged, rather than being passive audience. For all these reasons, many said that attendance mattered more in CST and MCST, rather than in more informal groups where some felt it was not as important if clients skipped sessions.

"The additional thing with MCST is that we are trying to do something therapeutic. So, we're trying to improve people's cognition, particularly by giving people these more targeted activities, rather than just make them feel better." - Expert interview

- **Evidence-based programme that is effective in dementia:** Staff and experts also stressed that another advantage of CST/MCST was that the programme was developed based on theory and evidence of what worked in dementia support; then tested and proven to be effective in having a positive impact on cognition and quality of life of people living with dementia. With its therapeutic aims and evidence-based approach, CST/MCST felt to be more clinical than other dementia support. Those Network Partners who worked closely with the NHS felt this set the programme apart and made them more likely to try and access NHS or local authority dementia-focused funding, where available. Experts who were clinicians also felt that CST/MCST gave newly diagnosed patients hope and control to try to slow down the cognitive decline through engaging in the programme. They also felt it enabled memory services and clinicians to provide more treatment post-diagnosis and not only medication, which they welcomed given the progressive nature of the disease and currently limited treatment options.

"I suppose the really big one is that it's evidence based. There's loads of research, it's global, it shows that it leads to significant benefits so that's really important. It may be that the other services are using similar components but we don't know exactly how effective that is, so following something evidence based is very helpful." - Expert interview

- **Standardised training and manual:** Another advantage highlighted in some expert and staff interviews was that the MCST programme came with the standardised training and the manual to support staff and service delivery. Respondents were not aware of other dementia support interventions that came with a similar 'package of support'. They felt this made it easier for staff at diverse organisations to deliver the MCST programme and ensure service consistency and quality control.
- **Varied activities:** Respondents across different groups (clients, carers, staff and experts) often commented that one advantage of MCST was that it offered varied activities that catered for different interests. They felt that this allowed MCST to engage a wider range of people living with dementia than individual activities, for example, singing or arts. An expert also pointed out that MCST combined best elements of different activities known to work well to stimulate and support people living with dementia.

"MCST is slightly different because it covers lots of different topics; because it's slightly smaller everybody can get more of a chance to participate; there's more brain work involved." - Carer

- **More personal:** Many clients, carers and staff also stressed that MCST groups allowed for a more personal experience and closer relationships to develop. In their small groups which felt comfortable, safe and familiar, people living with dementia were able to share their experiences of the condition and helpful tips with each other.

"This group is more personal, I don't know how to describe it really, they are all friends." - Carer

- **Continuity:** The regularity and frequency of sessions was also felt to compare favourably to some other services, for example, memory cafes. In addition to small group size, regularity and frequency of meetings also enabled clients to develop relationships and work towards improving and maintaining their cognition.
- **Independence:** Clients, carers and staff sometimes explained that MCST was different as it engaged people living with dementia on their own rather than with their carers. They felt this was very beneficial as it resulted in higher engagement from people living with dementia, as they communicated with others and solved tasks rather than allowing carers to step in. In the process, their independence was strengthened and they identified the skills they still possessed. Attending sessions on their own also felt empowering for people living with dementia, as this was something that was their time and activity.

"With all the other groups, I've got to attend as well so there's no independence there; with the MCST group they're independent then, aren't' they, so they can say what they want and without us being there." - Carer

- **Respite for carers:** MCST sessions were also compared to other dementia support services in terms of how much respite for carers they provided. They were seen to provide some respite for carers compared to many other activities where carers also had to be present, but less respite than day centres that lasted longer.
- **Targeting people living with mild to moderate dementia:** CST/MCST were seen as specific in providing support to people with mild to moderate dementia, which some felt addressed a gap in the post-diagnosis support. Others pointed out that Age UK's MCST was more flexible than NHS-provided CST in terms of eligibility criteria, so could support also people experiencing memory problems but who do not yet have a diagnosis.

CST/MCST in the broader landscape of dementia support

Age UK staff and experts interviewed for the evaluation most thought that MCST should be a part of a broader dementia support offer, rather than a standalone service. A range of services was felt to be needed to be able to support people living with dementia at different stages, starting from mild cognitive impairment to advanced dementia. Respondents saw MCST as a _'gateway'_ service that would be accessed prior to or immediately after the diagnosis (or following CST, where this was available).

"It should sit right at the beginning of someone's journey after having a diagnosis. The sooner you start to do activities the better it will be for you in the long run." - Staff

In this context, CST and MCST programmes were seen as key services for providing support to those with mild to moderate dementia and mild cognitive impairment, whereas day centres were central to supporting those with more advanced dementia. Respondents also explained these key services would be – and indeed were in some areas – complemented by other support: navigation services, dementia-friendly community activities, social activities and peer support groups, dementia outreach for those with advanced dementia who cannot attend day centres, and carer support.

The range of services respondents outlined and the place of CST and MCST within that offer is shown in the diagram below:
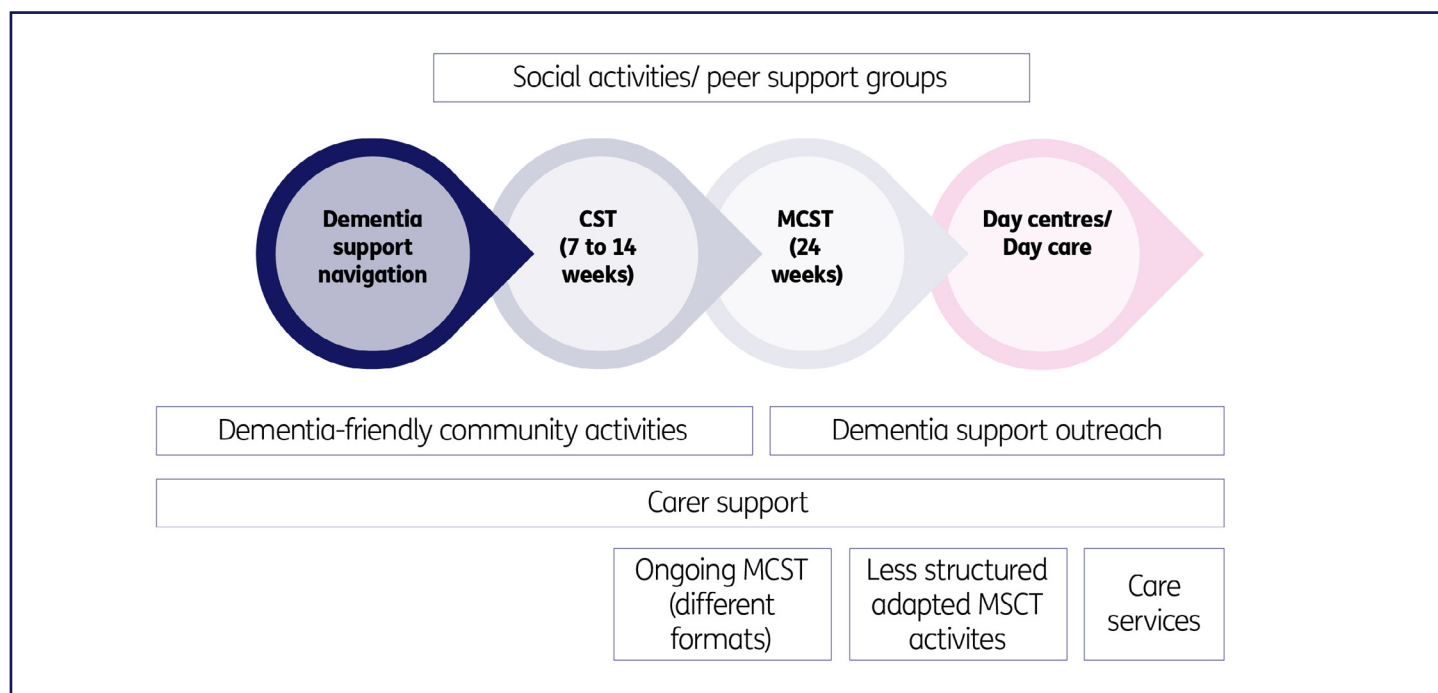
Figure 8: Where MCST fits in the broader landscape of dementia support

Thinking about support needs at different stages of dementia, some expert respondents pointed out that CST and MCST may not always be appropriate for people with mild cognitive impairment. Instead, it was suggested these people should be signposted to suitable mainstream, community activities to provide them with cognitive stimulation. Some staff and experts also raised the issue of stigma attached to dementia, with one reporting they stopped using the word 'dementia' in relation to their MCST services to overcome the barriers to accessing MCST in early stages of dementia.

"The target group for MCST is the most difficult group because they are still very able, so they naturally will not want to use any services. It is still manageable; this group does not think that they need any services. So, we try to convince them that this is not a centre, this is something that they are pro-actively doing for themselves so that they can keep their independence for as long as possible." - Expert interview

At the other end of the spectrum, some Age UK staff and experts supported the idea of embedding MCST activities and principles in activities in day centres. Where these were already in place, staff explained they were less structured, more relaxed and informal. MCST-based activities were seen to provide wellbeing and social benefits to people living with more advanced dementia, rather than cognitive improvement.

Staff and experts believed that MCST should continue after the initial 24 weeks, as the need for this support did not stop with the end of the programme. Different models were described for continuing MCST beyond the initial 24 weeks. In some instances, MCST groups carried on in the same vein, with a structured programme of activities which repeated some old ones and introduced new ones (developed by staff). Clients enrolled these groups on a rolling basis – as some left due to their condition deteriorating, new clients joined. In other cases, existing MCST groups continued meeting after the end of the 24-week programme but more as a peer-to-peer support group, including some MCST activities.

Thinking about different models of embedding MCST within the dementia support offer, some respondents argued that MCST could and should be linked to the support for carers. In this model, carers of MCST clients could be supported through peer support groups and information and advice services. Others also stressed the importance of providing online CST/MCST to allow access to this support to those living in areas where CST/MCST were not available or who struggled to access face-to-face sessions due to ill health, disability or transport barriers.

6: Conclusions and learnings for future MCST delivery

There was a strong belief among staff and expert interviewees that CST/MCST should be a mainstream, statutory service that should be available to all people living with dementia as post-diagnosis support. The argument for this was that CST/MCST was an evidence-based intervention that was proven to improve older people's quality of life and maintain their cognition, slowing down the decline.

Respondents struggled more with the question of who should be responsible for providing and funding CST/MCST services. There was some agreement that the NHS should be providing CST support, as part of the treatment offered post-diagnosis. Respondents thought it would be more difficult for the NHS to provide MCST, as a longer treatment that was potentially provided on an ongoing basis. Charity and non-profit organisations, such as Age UK, and potentially social care services were seen as more suitable providers of this ongoing support.

"The NHS just doesn't have capacity and they tend to offer short term treatments rather than long term care provision. The other thing is social care… there were day centres for people with dementia but a lot of them closed down and I don't think there's much funding in social care. So, community-based organisations like Age UK, it fits in perfectly. An ideal scenario would be to see it streamlined and have some kind of referral process from memory services into these ongoing Maintenance CST groups." - Expert interview

To access funding for such ongoing support, one expert highlighted the NHS policy and funding for long-term conditions as a potential route. If and where dementia was included in the policy as one of the long-term conditions, that could open up the way to fund MCST as ongoing support. The respondent also argued for raising awareness of CST and MCST in Integrated Care Boards (ICBs) that CST is a proven treatment like medication and deserves funding. There was some evidence that some Integration Joint Boards (IJBs) in Scotland have recognised the value of CST/MCST. For example, an expert from Scotland explained that CST and MCST in their area were funded by their IJB, using the funding for dementia support that was provided by the Scottish Government. In that instance, having evaluations of previous CST/MCST programmes which demonstrated their benefits helped IJB recognise their value.

With greater recognition of CST/MCST, some experts also felt that the idea of cognitive stimulation became more mainstream. While they mostly saw this as a positive development that potentially led to more provision for people living with dementia, they also thought it came with some risks. One expert thought the risk was that quality control was jeopardised and CST/MCST approaches diluted as more services promised to offer cognitive stimulation.

Ensuring that MCST staff had appropriate training and knowledge was therefore important for the service credibility. Respondents agreed this should include both the MCST training and more general dementia-focused learning and training. Many also liked the idea of introducing a skills and competence framework for those delivering MCST service. Respondents thought this would help with the uniformity of service and quality control, as well as give staff more confidence and more credibility to the service. One expert, however, warned that such a framework would need to be introduced carefully to avoid the risk of creating barriers to diverse staff being able to train in, and deliver, MCST service.

The evaluation provides evidence that the Age UK's MCST programme achieved its intended outcomes in relation to clients and staff, whereas the outcome concerning carers of people living with dementia was achieved to some extent.

Impact on clients' quality of life

- Quantitative research found clients' mean QOL-AD score increased following the intervention, suggesting that MCST clients' quality of life was improved. This finding confirmed previous research on CST and MCST.
- Qualitative research further showed that most clients, carers and staff felt that these improvements to clients' quality of life were significant. The evaluation identified key factors contributing to this improvement: social re-integration through the MCST programme; improved mood; learning how to live with dementia; and improvements in terms of self-esteem and motivation, independence, and orientation.
- Some groups experienced bigger improvements in quality of life than others, in particular: those attending face-to-face as opposed to online; those aged under 75 and within one year since diagnosis; clients with vascular dementia as opposed to other types of dementia whose QOL-AD scores remained stable; and those with less cognitive impairment, as suggested by their baseline and final SMMSE scores.

Impact on clients' cognition

- Comparisons between the baseline and final mean total SMMSE score in the MCST client sample suggested that their cognition levels largely remained stable over the period of the programme. Given the progressive nature of dementia where SMMSE scores typically decline between 2 and 4 points per year, the stable mean score over a period of 24 weeks confirms the protective character of MCST in slowing down cognitive decline.
- While the mean score remained stable, there were significant changes in terms of individual clients' scores and the extent of impairment they suggested. The most noticeable change in this respect was an increase in those registering mild cognitive impairment at the end of the programme when compared to the start. Specifically, 38% of clients whose baseline SMMSE scores indicated moderate dementia improved over the duration of the programme, as their final SMMSE scores suggested mild dementia or potentially no impairment. The increase in those with mild dementia at the end, however, also came from the group registering no impairment at the start, who declined slightly and moved to mild impairment.
- The quantitative findings suggesting the protective and beneficial impact of MCST were supported by qualitative research. Clients, carers and staff highlighted improvements across a range of different cognitive skills, however, carers and staff were less certain they could see improvements in terms of short-term memory.
- Evaluation findings also suggested a relationship between cognition, mood and quality of life, as the data indicated that those with better quality of life also improved cognitively more and the other way round.

Impact on carers

- Qualitative and quantitative data suggested somewhat different outcomes for carers. In qualitative research, carers reported the programme gave them some respite and they felt they benefitted in terms of their mood, wellbeing and quality of life. Quantitative data, however, suggested a slight worsening in carers' quality of life over time. In particular, final data suggested that there was a small deterioration in carers' overall quality of life, how well they felt they coped with the demands of caring, their relationship with the person they cared for, and support from family and friends.
- These opposite findings suggest that the programme conferred some benefits to the carers but that in most cases they were not significant enough to affect the carer situation so that their quality of life was improved. This may be as the programme did not specifically target carers through carer support, except in a small number of partners who offered carer support groups. In the future, such groups could potentially help carers cope better with the demands of caring through helping them access any other available support and providing emotional and psychological support.

Impact on staff knowledge, confidence and skills

- Staff felt the MCST training and programme improved their knowledge, skills and confidence to deliver MCST interventions.
- They highlighted the key areas where they felt their knowledge and skills improved: working with people living with mild dementia; ideas for materials and activities for people living with dementia; skills in running group sessions; and broader understanding of dementia and people living with dementia.
- Staff also shared some suggestions for improving training, guidance and resources for MCST staff, most notably, by making it more practical and interactive and providing guidance on how to adapt the programme.

Comparing face-to-face and online MCST

- There were some important similarities in terms of face-to-face and online MCST client experiences and outcomes, but also differences.
- Qualitative research found that both face-to-face and online MCST clients felt they benefited cognitively and in terms of their mood, wellbeing and quality of life. However, some differences were also identified: face-to-face MCST was felt to provide better social interaction and relationships than online MCST, whereas the latter gave the added benefit of improved digital skills to some clients.
- Quantitative data showed greater improvement in terms of quality of life for those attending face-to-face MCST, which may be explained by the greater social benefits mentioned above. Conversely, it also suggested there were cognitive improvements in the online MCST sample, whereas cognitive levels remained the same for those attending face-to-face MCST. These findings should be treated with caution, however, due to the small sample size of online MCST clients (No = 36). More future research is needed to understand the impact of online MCST quantitatively.
- The evaluation produced extremely rich findings regarding the ways to adapt the MCST programme and activities to online delivery. The practical solutions, ideas and approaches staff used to deliver MCST online would be useful to share across the Age UK network for future MCST delivery.
- As much as face-to-face MCST was seen to provide bigger benefits in terms of social interaction, the evaluation also highlighted the need for this to be complemented by online MCST. As some clients, carers and staff argued, online MCST has some unique benefits as it can reach a wider range of people living with dementia, most notably, those who are house-bound, have other barriers to accessing face-to-face sessions, or live in areas where CST and MCST are not provided.

How is MCST different from other dementia support

The evaluation highlighted some key ways in which CST and MCST were perceived to be different from other dementia support available. The following key differences were identified:

- Therapeutic aims – clear and explicit focus on improving cognition;
- Evidence-based approach that is effective in dementia, making it more clinical than other support;
- Standardised training and the manual supporting diverse staff to deliver the programme in a consistent way;
- Varied activities catering for diverse interests that can reach a wider range of people;
- More personal social and learning environment that is conducive to building social relationships and engaging in activities in a safe space;
- Continuity, regularity and frequency of sessions supporting the development of social relationships and skills;
- Independence, as people living with dementia participate on their own, without carers;
- Targeting people with mild to moderate dementia or mild cognitive impairment, which many felt would otherwise be a gap in dementia support provision.

Practical learnings for future MCST delivery

The evaluation also provided a range of practical feedback and learnings about what worked well and less well in different stages of programme delivery, from client referral and assessment, through other set-up activities, and delivering MCST sessions. The final part of conclusions pulls together some main practical learnings that could be helpful when delivering MCST in the future.

Client referral

- Referral pathways with 'warm contacts' with clients allowed for easiest client referral, however, may exclude potential clients with no prior contact with Age UK and partner services;
- Recruitment of people living with mild to moderate dementia or mild cognitive impairment can be challenging, as there are both barriers specific to people living with dementia and generic barriers to consider and overcome;
- To overcome some of these barriers, further awareness raising activities are needed so that MCST is more familiar both to potential clients and carers and health services and professionals who could refer them to Age UK;
- Promoting MCST to people living with mild dementia requires sensitivity to overcome any barriers because of the stigma of dementia;
- Network Partners should work to develop and grow their network and relationships with health services and other organisations working with people living with dementia, to establish strong local referral pathways for people living with dementia into their MCST programme;
- Motivations and barriers of people living with dementia for taking part in the MCST programme should be considered and reflected in promotion materials;
- Age UK National should consider how to support people who cannot access face-to-face MCST through exploring further possibilities to offer some online MCST.

Client assessment

- The measures that were used gave staff useful information to assess clients' suitability for the programme and understand their support needs.
- Administering assessment questionnaires was time-consuming and sometimes emotionally demanding for staff; therefore, such demands on staff should be factored in project planning and timescales.
- Some staff felt they needed more training on using the SMMSE questionnaire, suggesting that this aspect of staff training may need more attention in future delivery.
- The evaluation captured tips from staff on using the questionnaires with clients and carers, which would be useful to share across the Age UK network where appropriate.
- It may be helpful for Age UK National and Network Partners delivering MCST to reflect on the broader eligibility criteria and their implications, so that there is more clarity on implications of different criteria in terms of inclusion/ exclusion of clients and the requirements from staff.

Other set-up experiences

- Different partner experiences suggested that the set-up timescale should be relatively flexible as the time required to complete all the set-up activities is likely to vary across different partners and areas.
- There are barriers to access in both face-to-face and online MCST that need to be considered and addressed wherever possible, e.g. through well-connected and accessible venues, technical support for those attending online etc.
- Network Partners delivering MCST shared practical feedback that can be helpful when setting up and delivering MCST in the future, for example, tips on choosing a venue, timing and duration of MCST sessions, group formation and size. These should be shared across the Age UK network were appropriate.

Staff training

- Dementia-focused training and specialist MCST training were felt to have provided the knowledge and skills staff required to deliver the programme.
- The MCST training and manual could be further improved by providing more guidance on how to adapt the programme to online MCST and culturally diverse groups. There were also suggestions that making the training more interactive and practical would be helpful to staff.

Service delivery

- The MCST programme of activities was evaluated extremely positively by clients, carers and staff. Clients enjoyed that the programme provided varied activities of suitable difficulty, which enabled them to work together and become more confident in using their various cognitive skills.
- Clients and staff also provided useful practical feedback on individual activities and their delivery that may be helpful to staff providing MCST in the future.
- The programme needed to be adapted for online delivery, with some activities working better online than others. The evaluation captured some practical learnings around key ways to adapt the activities and helpful tips for delivering them online, which could be shared across the Age UK network where appropriate.
- Staff thought it would be helpful if some of the resources developed and used in MCST programmes could be made accessible to Age UK network, so other partners could benefit and build on them.
- The evaluation highlighted some key features of the Age UK's MCST programme that were seen as essential to its positive impact and benefits. These included: small-group dynamic that stimulated social interaction and relationships; structure, regularity and continuity of sessions; and staff who were extremely supportive and skilled at working with people living with dementia.
- Staff also highlighted some key challenges in MCST service delivery to consider: managing differences within MCST groups, for example, in terms of different levels of dementia, age, gender or ethnicity; coping with certain time-intensive aspects of preparing for MCST sessions; and meeting support needs of clients, which were sometimes considerable.

Appendix 1: Qualitative and quantitative samples for the evaluation

Sample

Cohort 1, 2 and 3 qualitative sample included a mix of clients, carers and staff as follows:

Client and carer sample:

- Cohort 1: *No = 35 respondents (18 clients, 17 carers)*
- Cohort 2: *No = 40 respondents (20 clients, 20 carers)*
- Cohort 3: *No = 50 respondents (29 clients, 21 carers)*

Sample criteria (based on clients)		Cohort 1 No of interviews	Cohort 2 No of interviews	Cohort 3 No of interviews	All
Gender	Male	10	12	16	38
	Female	10	6	13	29
Age	Under 75	6	1	6	13
	Over 75	14	10	16	40
	Unknown	/	9	7	16
Ethnicity	White British	13	20	27	60
	White Other	1	0	0	1
	Asian / Asian British	3	0	2	5
	Black African / Caribbean / British	1	0	0	1
Type of dementia	Alzheimer	6	6	7	19
	Vascular	2	3	1	6
	Other	1	/	1	2
	Not diagnosed	1	/	4	5
	Unspecified*	8	11	16	35
How MCST delivered	Face to face	13	19	16	48
	Online	5	1	13	19

*This information was not always provided about clients who took part in the interviews.

Qualitative research included clients from different MCST partners:

- 12 Cohort 1 Network Partners: Berkshire, Calderdale and Kirklees, County Durham, Cymru Dyfed, Enfield, Hythe, Lyminge & Ashford, Lancashire, Milton Keynes, Salford, Somerset, Sunderland, and Tameside.
- 14 Cohort 2 Network Partners: Barnsley, Bournemouth, Poole & East Dorset, Bristol, Kensington & Chelsea, Leeds, Leicester, Northern Ireland, Portsmouth, Scarborough, Scotland Orkney, Sheffield, South Kent Coast, Wakefield, Westminster.
- 11 Cohort Network Partners: Bedfordshire, Blackburn & Darwen, Camden, Carlisle & Eden, Cheshire, Coventry & Warwickshire, Cymru Dyfed, North Tyneside, Sheppey, Wandsworth, Wirral. In addition, clients who attended online MCST delivered by Age UK National Telephone Friendship Service also took part in the evaluation.

Staff sample – No = 75 (Cohort 1 - 26 respondents; Cohort 2 – 23 respondents, Cohort 3 – 26 respondents)

The staff sample was split as follows based on whether they delivered face-to-face or online MCST:

Mode of delivery	Cohort 1	Cohort 2	Cohort 3	Total
Face-to-face	16	21	20	57
Online	5	/	3	8
Both	5	2	3	10

Staff from 18 Cohort 1 Network Partners were interviewed, including: Berkshire, Birmingham and Sandwell,Calderdale and Kirklees, County Durham, Cymru Dyfed, Doncaster, East London, Enfield, Hythe Lyminge & Ashford, Lancashire, Lincoln & South Lincolnshire, Milton Keynes, Northumberland, Salford, Somerset, Sunderland, Tameside, and Worcestershire and Malvern Hills.

Staff from 18 Cohort 2 Network Partners were interviewed, including: Barnsley, Bournemouth Poole and East Dorset, Bristol, Cheshire East, Faversham & Sittingbourne, Hereford & Worcestershire, Leeds, Leicester, Northern Ireland, Portsmouth, Reading, Scarborough, Scotland Orkney, Sheffield, South Kent Coast, Surrey, Wakefield, Westminster.

Staff from 15 Cohort 3 Network Partners were interviewed, including: Blackburn & Darwen, Bedfordshire, Camden, Carlisle & Eden, Cheshire, Cymru Dyfed, Gateshead, Hythe, Lyminge & Ashford, Milton Keynes, North Tyneside, Sheppey, Somerset, Trafford, Wandsworth, Wirral. In addition, Age UK National Telephone Friendship Service staff were also interviewed.

Cohort 1, 2 and 3 quantitative samples were based on available assessment data which programme partners collected from clients:

The sample of those who completed SMMSE assessments was split as follows:

Sample criteria		Cohort 1		Cohort 2		Cohort 3	
Sample size by cohort		62		123		165	
Gender	Male	28	45%	50	41%	66	40%
	Female	34	55%	65	53%	70	42%
	Unknown*	/	/	8	7%	29	18%
Age	Under 75	17	27%	30	24%	51	31%
	Over 75	45	73%	82	67%	84	51%
	Unknown	/	/	11	9%	30	18%
Ethnicity	White British	58	93%	112	91%	106	64%
	White Other	1	2%	3	2%	3	2%
	Asian / Asian British			1	1%	0	/
	Black African / Caribbean / British	3	5%	1	1%	3	2%
	Unknown			8	6%	53	32%
Type of dementia	Alzheimer	18	29%	51	39%	44	27%
	Vascular	12	19%	14	11%	16	10%
	Other types of dementia	21	34%	34	28%	53	32%
	Not diagnosed	11	18%	17	14%	14	8%
	Unknown			7	6%	38	23%
How MCST delivered	Face to face	52	84%	120	98%	142	86%
	Online	10	16%	3	2%	23	14%

*There was no data available on demographic characteristics for some clients in Cohorts 2 and 3. The number of clients whose demographic data was unknown is shown in the table above.

The sample of those who completed QOL-AD participant assessments was split as follows:

Sample criteria		Cohort 1		Cohort 2		Cohort 3	
Sample size by cohort		74		136		167	
Gender	Male	33	45%	54	40%	69	41%
	Female	41	55%	70	51%	70	42%
	Unknown*	/	/	12	9%	28	17%
Age	Under 75	20	27%	30	22%	50	30%
	Over 75	54	73%	89	65%	88	53%
	Unknown	/	/	17	12%	29	17%
Ethnicity	White British	70	95%	119	87%	109	65%
	White Other	1	1%	3	2%	4	2%
	Asian / Asian British	/	/	2	1%	0	0%
	Black African / Caribbean / British	3	4%	2	1%	3	2%
	Unknown	/	/	10	7%	51	30%
Type of dementia	Alzheimer	20	27%	54	40%	44	26%
	Vascular	15	20%	14	10%	16	9%
	Other	25	34%	36	26%	60	36%
	Not diagnosed	14	19%	22	16%	10	6%
	Unknown	/	/	10	7%	37	22%
How MCST delivered	Face to face	64	86%	133	98%	145	87%
	Online	10	14%	3	2%	22	13%

* There was no data available on demographic characteristics for some clients in Cohorts 2 and 3. The number of clients whose demographic data was unknown is shown in the table above.

Quantitative data were collected from:

- 12 Cohort 1 Network Partners: Berkshire, Birmingham and Sandwell, Blackburn and Darwen, Calderdale and Kirklees, County Durham, Cymru Dyfed, Doncaster, Gateshead, Lincoln & South Lincolnshire, Northumberland, South Gloucestershire, Sunderland;

- 24 Cohort 2 Network Partners: Barnsley, Bexley, Bournemouth Poole and East Dorset, Bristol, Cheshire East, Devon, Faversham & Sittingbourne, Hereford & Worcestershire, Hertfordshire, Kensington & Chelsea, Leeds, Leicester, Norwich, Northern Ireland, Portsmouth, Reading, Scarborough, Scotland Orkney, Sheffield, South Kent Coast, Surrey, Teesside, Wakefield, Westminster.

- 19 Cohort 3 Network Partners: Barrow, Bedfordshire, Berkshire, Blackburn & Darwen, Camden, Carlisle & Eden, Cheshire, County Durham, Cymry Dyfed, Gateshead, Hythe, Lyminge & Ashford, Milton Keynes, North Tyneside, Sheppey, Somerset, Tameside, Trafford, Wandsworth, Wirral. In addition, the Age UK National Telephone Friendship Service also provided quantitative data for their clients.

Appendix 2: Discussion guides

2143 AGE UK DEMENTIA MCST EVALUATION

PARTICIPANT AND CARER DISCUSSION GUIDE (6-MONTH FIELDWORK POINT) [20]

Sessions will last 45 minutes and will follow largely the same structure and content as the interviews conducted with participants at 3 months.

1: Introduction (10 minutes)

Note: moderator needs to explain the below to comply with GDPR and the MRS code of conduct however the moderator will tailor the explanation to the participant and ensure that it is clear.

I am here today on behalf of Age UK to find out about your experiences of the Maintenance Cognitive Stimulation Therapy sessions you have been attending. We want to talk to you about what you liked about these sessions and if there is anything you think could be improved. We would also like to talk to you about what difference these sessions have made for you.

To speak to you today I have your name and contact details which is personal data. This will be held securely by my company for the purposes of this research project only and will be deleted after 6 months.

I would like to record this conversation today on my digital recorder. The recording is taken so I can listen back and write notes of this interview and will not be shared with Age UK. When we report back to Age UK, we will ensure that your feedback is anonymous. This audio recording is held securely for 12 months, then deleted. You have the option to request earlier deletion of this information or to see the information we have recorded by getting in touch with us directly.

The most important thing is that you are comfortable during this conversation, you have the right not to answer any question and if you would like me to stop the conversation at any time or take a break please let me know.

As a thank you for participating in this research today you will receive £x incentive which we will [give to you today/ transfer to your bank account].

Invite any questions about the research or the process and ask participants if they are happy to continue.

Invite respondents and their carer to introduce themselves:

- Name and how they like to spend their time

Today I will be asking both of you questions about your experience of the MCST sessions.

I will address some of my questions to you [*name of participant*] but if you would like to check something with your [insert relationship to carer or name], please do. If there is a question you do not think you can answer please tell me and please don't worry, we can see if your [*carer*] knows the answer and if not, it doesn't matter.

I have some specific questions for [carer] which I will ask today but please do contribute to the questions I ask [name of participant] too if you would like to as your input would be valued.

2: Establishing the context (10 minutes)

Note: It would be helpful to understand how the participant came to hear about the MCST sessions and the process they went through to sign up, as far as this is possible. If the participant is not able to recall this information, please ask the carer if they know and if not, move to the next section.

- How did you first hear about the sessions?
- What were you hoping to get out of the sessions when you signed up?
- What difference did you hope the sessions would make for you? *Prompt: what issues was participant hoping that the sessions would address. Take note of these as prompts for future interviews*
- Tell me a bit about the process of signing you up to join the sessions. What information did you have to provide? How did the process work?
- Did you have to answer any questions about yourself or complete any tasks? *e.g. assessments such as SMMSE/ QOL-AD or others*
- ° If Yes: How did you find completing doing this? What did you like? Anything you didn't like?
- When did you start attending the MCST sessions?
- How many have you attended so far roughly?

3: Practicalities and access (5 minutes)

- Have you attended sessions face to face or virtually?
- How have you found accessing these sessions?
- ° *Prompt the following for face to face:*
- – Suitability of the venue? Access, location, the venue itself.
- – Transport to and from the venue
- ° *Prompt the following for virtual sessions:*
- – Any IT challenges or issues
- – Ease of usage of chosen virtual platform *e.g. Zoom, google meet etc.*

4: Likes and dislikes of the MCST sessions (5 minutes)

- Tell me a bit about the sessions you have attended. *Allow spontaneous comment*
- What types of activities have you done? *Moderator to show stimulus if helpful to remind respondents of MCST activities*
- What did you like most about the sessions? *Prompt with sessions from the manual if needed.*
- What did you not like as much?
- What was your favourite session so far and why?
- What did you think of the way the sessions were run? *Prompt: structure of the sessions, approach of person leading the sessions*
- ° What worked well in the sessions?
- ° Is there anything you think worked less well or could have been better?

- [Ask the carer]:
- Were you given any information on activities [insert the participant's name] did at their MCST group?
- ° Probe to understand what information they were given, if any
- ° What did you think about that information?
- ° What was helpful / less helpful about it?
- ° [If they were given information] Did you use this in any way? *Probe to understand if they used information on activities to carry on doing this with the participant at home*

5: Future of the MCST sessions (5 minutes)

- Do you know whether the sessions due to continue or have they now stopped?
- If due to continue:
- ° Do you intend to carry on attending them? Why/why not?
- ° How do you feel about the fact the sessions are carrying on?
- If no:
- ° How do you feel now the sessions have come to an end?
- ° What impact do you believe this will have on you?
- ° Are you planning to attend any other activities? Which? How do these compare to the MCST sessions?

6: Impact on participant (10 minutes)

I would like to talk now about the impact that attending the MCST sessions has had on you so far.

- Do you think attending these sessions has made a difference to you? How? *Allow spontaneous comment*
- Thinking back to when you started attending the sessions through to now, do you think the difference the sessions has made has changed in this time? Or stayed the same?

- *Ask the below questions for each of these 4 factors:*
1. Your mood
2. How well you feel in yourself (Wellbeing)
3. Your quality-of-life Prompt the following if phrase confuses happiness, health, comfort
4. Your memory and mental functioning
- Do you think attending the sessions has made a difference to [insert above]?
- If yes:
- ° In what way?
- ° What about the sessions has made that difference do you think?
- ° When did you first notice this difference? *Prompt: was it straight away, or after a few sessions or more recently?*
- ° How long did this change last for? *Moderator to sensitively explore to understand how long any positive impact lasted*
- If no:
- ° Why not?
- ° Is there anything that could be changed or improved about the sessions to ensure they do improve *[insert above]* for you?

- Do you attend any other groups or sessions aimed at those living with dementia? Tell me a bit about them.
- How do they compare with the MCST sessions you have attended? *Prompt:*
- ° What do you like more about the other groups and sessions?
- ° What does MCST do better than the other groups and sessions?
- Do you think the MCST sessions should be a separate service for people with dementia or linked with other services that are offered for people with dementia? For example, people might be encouraged to use more than one service, or attend different groups or sessions on the same day?

7: Impact on carer (5 minutes)

I would like to talk now about the impact of the MCST sessions on [carer].

- What impact do you think [*participant*] attending these sessions has had on you? *Allow spontaneous comment then prompt:*
- º Have you had any respite as a result of the programme?
- º Have you participated in any activities or sessions as a result of the MCST programme? *Prompt: for example, any other Age UK activities, or other organised activities as a result of respite offered by the sessions. If Yes probe:*
- – Tell me a bit more about those?
- – What worked well? What didn't work so well?
- º Has it had any impact on your relationship with [insert participant name]? If yes, how?
- º Have you experienced any positive impacts as a result of the programme?
- º Have you experienced any negative impacts as a result of the programme? *Prompt: as a result of involvement in virtual sessions and any IT issues*
- Did you meet with any other carers of participants in the MCST programme? If yes: Tell me a bit more about that? Did meeting others help you in any way? How?

- *Ask the below questions for each of these 3 factors:*
- 1. Mood
- 2. Wellbeing
- 3. Quality of life
- Do you think attending the sessions has had a positive impact on your [*insert above*]?
- If yes:
- º In what way?
- º What about the sessions has made that impact do you think?
- º When did you first notice this impact? *Prompt: was it straight away, or after a few sessions or more recently?*
- º [As relevant] How long did change last?
- If no:
- º Why not?
- º Is there anything that could be changed or improved about the sessions to ensure they do improve [*insert above*] for you?

8: Conclusions (Remaining time)

- Other local Age UKs around the country will be running these sessions are soon. What advice would you give the people running them?
- What would they need to do to make sure these sessions work for others who join them?
- Is there anything else you would like to feed back about the sessions you have attended?

THANK AND CLOSE

2143 AGE UK DEMENTIA MCST EVALUATION

STAFF DISCUSSION GUIDE

Note: This discussion guide is to be used for focus groups and depth interviews with staff, but suggested timings relate to the focus groups (1.5 hours in length)

1: Introduction and permissions (10 minutes)

Age UK are conducting an evaluation of the Dementia MCST programme and that is why we would like to talk to you today. As well as identifying if the programme has improved wellbeing and cognitive abilities of those living with mild and moderate dementia, the evaluation is looking to determine whether the programme has improved knowledge, skills, and confidence in delivering MCST-based interventions for staff and volunteers.

We would like to talk to you today about your experiences delivering the programme including successes and any challenges, as well as discussing the effectiveness of the training.

Before we start chatting, we need to explain a few points to you.

Your personal data (i.e. your name and work email address) will be held securely by Research Works Limited (the data processor) for the purposes of this research project only. Your personal data will be held by us for 6 months, then deleted. It will not be shared with any other third party.

Please be open and honest with your feedback today, we want to hear what you really think! The research session is confidential and all the feedback you give today will be shared on an anonymous basis with the Age UK MCST programme team – you and your individual organisation will not be identifiable within the report and none of the comments you make will be attributed to you or your organisation.

We would like to ask permission to record this interview:

- Your audio data will be used and stored securely for the purposes of this research project only.
- It will be analysed (non-digitally) and the findings will be reported back to the Age UK MCST programme team in a way that means you are anonymous to them.
- It will be held by us securely for 12 months, then deleted. It will not be shared with any third party.
- You have the option to request earlier destruction of your information, or to see the information we have recorded about you, by getting in touch with us directly.

The most important thing is that you are comfortable during this conversation, you have the right not to answer any question and if you would like me to stop the conversation at any time or take a break please let me know.

Please start by giving us a **brief introduction of yourself** including your first name, your role within the organisation, your role in the MCST programme and whether you are running face to face or virtual MCST sessions or both.

2: Recruitment of participants for the MCST sessions (10-15 minutes)

Explain that we would first like to talk about the process of setting up the sessions and what the successes and challenges were.

- Tell me a bit about how you identified suitable older people to take part in the sessions?
- What **referral pathways** did you use?
- *Prompt as examples: existing users, dementia advisors, social prescribers, GPs, VCFS (voluntary, community and faith sector), local carers centre, NHS memory clinics*
- How many of these referral pathways were new? And how many had you used before? Probe: Any challenges associated with new referral pathways?
- Which referral pathways have been most successful? And which least? Why?
- Have the referrals you have received been appropriate? Why/why not
- What learnings have you taken from the referral pathways you have used?
- What type of partnerships have you used? Are any of these new?

- Did you **promote the service** in any way? How?
- *Prompt as examples: Alzheimer's Society Memory Café, local support groups etc*
- Which methods of promotion have been most successful? And which least?
- What challenges, if any, have you faced in promoting the service?
- What learnings have you taken from promoting the service?

- How long did it take you to recruit enough people for your groups?
- How did you feel about that length of time?

- What were your experiences of using the SMMSE questionnaire to determine the suitability of a participant?
- What worked well with this tool?
- Anything that was challenging or didn't work as well?
- What were your experiences of the tools used to determine wellbeing? Probe for QOL-AD and CDEMQOL separately
- What worked well with this tool?
- Anything that was challenging or didn't work as well?

3: Set-up of the MCST sessions (5-10 minutes)

- *Reminder:* Is your organisation running virtual sessions or face to face sessions or both?
- Tell me a bit about what worked well when setting up the sessions? *Prompt: finding a suitable venue, contacting participants, IT set-up*
- Was there anything that didn't work well or was challenging when setting up the sessions? *Prompt: participant availability, challenges finding a suitable venue, recruiting staff, IT issues, participant/carer knowledge of remote call system*

4: Training (10-15 minutes)

- What were your experiences of the **MCST training** aimed at Project Lead's? *Prompt and tailor depending on respondent role, e.g. whether Project Lead or member of staff running sessions*
- º Did this prepare the Project Lead's well to run the sessions? *Prompt for both face to face and virtual sessions*
- º What did you think of the structure of the training?
- º And the content? Anything missing?
- º Did this training give you enough **knowledge** on the MCST approach? Why/why not?
- º Did it equip you with the **skills** you needed to run the sessions? Why/why not?
- º After completing the training did you feel you had the **confidence** to go away and run these sessions? Why/why not?
- º After completing the training did you refer to any resources or other sources of information for follow up questions you had? What did you use?
- º What did you think of the training being delivered on zoom?
- º Would a follow-up / refresher (perhaps annually) be useful? Why/why not?

- Has your organisation taken part in the **cascade training (train the trainer)** so that trained staff can pass on Dementia training to the rest of the organisation? *Moderator to remind respondents this training was delivered by Buz Loveday from Dementia Trainers, so they're clear which training we're discussing* [21]
- º If yes:
- - What encouraged you to take part in this?
- - What worked well with the training?
- - Anything that didn't work well?
- - Has the training been useful? *Prompt: have they been able to pass the training on*
- - *Prompt views on these elements raised in feedback if needed:*
- · Videos
- · Course activities
- · Practice sessions and feedback provided for those running sessions
- · Information pack
- · Overall atmosphere/ level of support
- · Format – zoom and any challenges with this
- · Length of the sessions
- º If no:
- - Why has your organisation not taken part in this so far?
- º The target is for 2 people within your organisation to complete this and deliver 2 sessions by 13th October 2023, do you think you will meet this target? Why/why not?
- º Has this training been cascaded to other colleagues across your organisation?

- Has anyone in your organisation completed the **Dementia e-learning** yet?
- º If yes:
- - Do you know how many people completed this training?
- - What encouraged them to take part in this?
- - What worked well with the training?
- - Anything that didn't work well?
- - Has the training been useful?

- º If no:
  - – Why has your organisation not taken part in this so far?
  - • Have you used the Making the Difference Guide 2 manual? Why/why not?
  - º If yes: How helpful have you found this?

5: Running the MCST sessions (20 minutes)

Explain we would now like to discuss their experiences of running the sessions and what the successes and challenges have been.

- • What activities did you run as part of the sessions you have completed so far? *Establish the context before looking at what has and hasn't worked well.*

- • What has worked well in running the sessions from your perspective? *Allow spontaneous comment and probe the below examples taken from monitoring reports if needed*
- º Participant enjoyment
- º Participants forming friendships and bonding in the session
- º Carers forming friendships and bonding in the session
- º Discussing learnings with other partners running MCST sessions
- º Participants improving engagement or cognitive ability

- • What have been the challenges in running the sessions? *Allow spontaneous comment and probe the below examples taken from monitoring reports if needed*
- º Participants dropping out
- º Participants not being able to attend sessions owing to personal circumstance e.g., illness, not able to travel to venue
- º Participants not able/ not willing to pay for the service
- º Issues with the venue for the sessions
- º IT issues either for participants or those running session
- º Staff holidays
- º Staff sickness and COVID-19 related absence
- º Staff leaving

- • Which activities have worked particularly well?
- • Any activities that have worked less well?

- • Have you heard any feedback from participants taking part in the programme or their carers?
- º What have they found positive about the programme?
- º Any challenges they have expressed?

- • What information were carers given about activities participants did, if any?
- º Did you hear any feedback from carers about this information?
- º Do you know if carers use this in any way, e.g. to talk about these activities to participants?

- What is your view of the **impact of the sessions** on participants in the following ways:
° Cognitive abilities?
° Wellbeing?
° Quality of life?
- What about for carers – what is your view of the impact of these sessions on
° Carer wellbeing?
° Carer quality of life?
° Carer mood?

- [For any impact mentioned] Do you have any sense of how long that change / impact lasted for?
° Are some of these changes short-term? Are there any that last longer?

6: The place of MCST in dementia-support landscape (10 minutes)

- Are you familiar with any other dementia-related support services? *Explain that this could be through working in other services, or overseeing them, through training or otherwise*
° What other dementia-related support services are you familiar with, if any?
° In your experience, how does MCST differ from these other services? *Moderator to listen to spontaneous responses, then probe:*
- In terms of its impact on participants?
- In terms of its impact on carers?
- In terms of practicalities involved in its delivery?
- Challenges and successes?
- In your experience / from what you've observed, how does MCST differ from these other support services in terms of:
° Providing added value / offering something unique?
° What added value it brings?
° How that's achieved?
° Who this added value is for, e.g. people with dementia, their carers?

- Do you see the MCST sessions as a **cohesive part of a broader service for people with dementia** or do you feel it is more of a standalone service? Why? *Prompt: does it link well with other services for people with dementia*
- What are your views on the **delivery costs** of the MCST programme so far? *Prompt: when considered alongside the impact of the programme*
° *Moderator note: project leaders may not be able to answer this question. If not, ask to follow up with CEO if possible.*
- Do you have any plans to **continue the sessions** once the 6 months is up? Why/why not?
° If so, how? *Prompt: for example new groups, change of venue/ time/ date, charging etc.*

Moderator note: project leaders may not know the answer to this question. If not, ask to follow up with the CEO if possible

7: Differences between virtual and face to face sessions (5-10 minutes)

We would like to discuss the merits and challenges of virtual and face to face MCST sessions.

Moderator note: cover in more detail with those who ran virtual sessions or both virtual and face to face, and cover more briefly with those who only ran face to face.

Ask those organisations running both face to face and virtual sessions (note – just Berkshire and Wirral in Cohort 3):

- What are the differences in the set up between face to face and virtual sessions?
- Which session has been **easier to set-up** – the face to face or virtual? Why?
- Which session was **easier to recruit participants to or receive referrals into**? Why?
- What are the differences in running face to face and virtual sessions?
- Which session has been **easier to run**? Why?
- Have you noticed any differences in **participant experience** between the face to face and virtual sessions?
- Have you seen any differences in the **impact on participants**? *If yes:* Why do you think this is?

Probe the below questions for face to face and virtual sessions in turn, asking all participants:

- If you were to give advice to the next cohort of partners on setting up a [face to face/virtual] session what would you say?
- What advice would you give on running a [face to face/virtual] session?
- [As relevant] What made you decide to run face to face as opposed to virtual sessions or vice versa?
- What do you see as the benefits of face-to-face sessions? Any drawbacks to running the sessions face to face?
- What are the benefits of virtual sessions? Any drawbacks to running the sessions virtually?

8: Reflection on staff and volunteer personal development (5 minutes)

- Thinking back across your journey to date setting up and running MCST sessions, I am going to list three things and I would like you to tell me if you think your involvement in these sessions has improved this for you, or not, and why:

1. Your knowledge of MCST based interventions
2. Your skills in delivering MCST based interventions
3. Your confidence in delivering MCST based interventions

- Are there any learnings that could be taken ahead to future partners delivering these sessions to improve any of these three things for the staff and volunteers who are involved?

THANK AND CLOSE

Appendix 3: MCST programme clients' demographic profile

1061 clients took part in the MCST programme across the three cohorts. Their demographic profile is shown in the tables below.

Gender	Number of clients	% of clients
Male	507	48%
Female	542	51%

Base: 1049

Age	Number of clients	% of clients
50-60	23	2%
61-70	126	12%
71-80	450	44%
81-90	359	35%
91-100	49	5%
100+	2	0%

Base: 1009

Ethnicity	Number of clients	% of clients
White British	877	89%
White Other	33	3%
Asian / Asian British	23	2%
Black / Black British	28	3%
Mixed ethnic background	20	2%

Base: 981

Type of dementia	Number of clients	% of clients
Alzheimer's	353	44%
Vascular	146	18%
Mixed	149	19%
Other	110	14%
Not diagnosed	34	4%

Base: 792

Years since diagnosis	Number of clients	% of clients
Less than 1	122	28%
1	92	21%
2	86	19%
3	58	13%
4	30	7%
5	18	4%
Over 5	34	8%

Base: 440

Living arrangements	Number of clients	% of clients
Living alone	294	30%
Living in a couple	531	54%
Living with family / friends	113	11%
Living with non-family / non-friends	9	1%
Other	41	4%

Base: 988

Have clients previously had CST	Number of clients	% of clients
Yes	232	22%
No	731	70%
Unknown	74	7%

Base: 1037

Have clients had previous contact with Age UK	Number of clients	% of clients
Yes	570	55%
No	463	45%

Base: 1033

Appendix 4: Assessment data summary tables

The tables below provide more information on those assessment measures and questions where changes were observed in clients' or carers' responses between the start and end of the programme. Any statistical differences are highlighted. Data where differences between baseline and final scores were minimal or there was no change is not included here. Please note that in all cases the baseline and final samples included the same clients.

1: QOL-AD (client version)

Changes in mean total QOL-AD score – all clients who completed QOL-AD			
Base: 377	**Baseline (s.d.)** [22]	**Final (s.d.)**	**Difference**
Mean total score	34.45 (6.91)	35.22 (6.77)	+0.77
Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.			

S.d. = Standard deviation.[22]

QOL-AD questions where changes were observed between baseline and final data			
Question (Base)	**Baseline**	**Final**	**Difference**
Question 3. Mood (373)			
Poor	9%	8%	-1%
Fair	36%	31%	-5%
Good	47%	52%	+5%
Excellent	8%	10%	+2%
Mean score	2.53 (s.d. 0.76)	2.64 (s.d. 0.77)	+0.11
Question 5: How they feel about their memory (376)			
Poor	23%	21%	-2%
Fair	51%	46%	-5%
Good	23%	31%	+8% *
Excellent	4%	2%	-2%
Mean score	2.07 (s.d. 0.78)	2.13 (s.d. 0.76)	+0.06
Question 6: How they feel about family and family relationships ((374)			
Poor	7%	7%	None
Fair	10%	9%	-1%
Good	42%	48%	+6%
Excellent	41%	36%	-5%
Mean score	3.17 (s.d. 0.88)	3.13 (s.d. 0.85)	-0.04
Question 11: Ability to do things for fun, that they enjoy (375)			
Poor	12%	8%	-4%
Fair	30%	28%	-2%
Good	46%	47%	+1%
Excellent	13%	17%	+4%
Mean score	2.59 (s.d. 0.86)	2.73 (s.d. 0.84)	+0.14 *
Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.			

Changes in mean total QOL-AD scores by different client groups			
Variable (Base)	**Baseline (s.d.)**	**Final (s.d.)**	**Difference**
Cohort (Base)			
Cohort 1 (74)	34.09 (6.01)	35.24 (6.19)	+1.15
Cohort 2 (136)	34.35 (7.22)	34.6 (7.79)	+0.25
Cohort 3 (167)	34.69 (7.06)	35.71 (6.09)	+1.02
Delivery mode (Base)			
Face-to-face (340)	34.59 (6.96)	35.44 (6.68)	+0.85
Online (35)	33.06 (6.57)	33.06 (7.48)	None
Gender (Base)			
Male (156)	34.02 (6.75)	34.85 (6.36)	+0.83
Female (181)	34.62 (7.23)	35.33 (7.25)	+0.71
Age (Base)			
Under 75 (101)	33.76 (7.63)	35.25 (6.95)	+1.49
Over 75 (229)	34.51 (6.78)	34.98 (6.86)	+0.47
Living arrangements (Base)			
Living alone (110)	34.08 (7.11)	34.71 (7.16)	+0.63
Living with others (230)	34.44 (6.96)	35.28 (6.68)	+0.84
Type of dementia (Base)			
Alzheimer (118)	35.59 (6)	36.08 (6.45)	+0.49
Vascular (45)	32.44 (8.49)	35.47 (5.96)	+3.03
Other types (99)	34.13 (6.97)	33.65 (6.29)	-0.48
Not diagnosed (60)	34.38 (6.14)	35.68 (8.03)	+1.3
Years since diagnosis (Base)			
Less than 1 year (166)	33.48 (7.83)	34.73 (7.65)	+1.25
1-5 years (147)	35.24 (5.85)	35.31 (5.84)	+0.07
Had CST support previously or not (Base)			
Yes (72)	35.06 (6.5)	34.64 (6.78)	-0.42
No (246)	34.1 (6.99)	35.22 (6.68)	+1.12
Had prior contact with Age UK or not (Base)			
Yes (194)	33.7 (7.94)	34.41 (7.18)	+0.71
No (138)	35.07 (5.4)	35.95 (6.35)	+0.88
Baseline mean total QOL-AD score (Base)			
Lower than average (153)	27.97 (5.45)	30.46 (5.96)	+2.49 **
Higher than average (204)	39.35 (3.24)	38.9 (5.07)	-0.49
Baseline SMMSE total score [23] (Base)			
Moderate dementia (127)	33.89 (6.39)	34.38 (6.2)	+0.49
Mild dementia (81)	34.78 (7.21)	36.19 (6.78)	+1.41
No impairment (125)	34.7 (7.4)	35.25 (6.59)	+0.55
Final SMMSE total score (Base)			
Moderate dementia (90)	32.81 (7.82)	33.07 (6.2)	+0.26
Mild dementia (134)	35.41 (6.07)	35.88 (6.37)	+0.47
No impairment (104)	34.52 (7.12)	36.26 (6.55)	+1.74

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

Base size for those whose SMMSE scores indicated severe cognitive impairment was too small to allow for sub-group analysis.[23]

2: QOL-AD (carer version)

Changes in mean total QOL-AD score – all carers who completed QOL-AD			
Base: 209	**Baseline (s.d.)**	**Final (s.d.)**	**Difference**
Mean total score	32.18 (6.94)	32.57 (7.07)	+0.39

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

QOL-AD questions where changes were observed between baseline and final data			
Question (Base)	**Baseline**	**Final**	**Difference**
Question 3: Carers' view on clients' mood (207)			
Poor	12%	6%	-6% *
Fair	43%	45%	+2%
Good	42%	44%	+2%
Excellent	3%	5%	+2%
Mean score	2.35 (s.d. 0.73)	2.48 (s.d. 0.68)	+0.13
Question 6: Carers' view on how clients feel about family and family relationships (207)			
Poor	10%	9%	-1%
Fair	13%	8%	-5%
Good	43%	46%	+3%
Excellent	34%	36%	+2%
Mean score	3.02 (s.d. 0.93)	3.1 (s.d. 0.9)	+0.08

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

3: SMMSE

Changes in mean total SMMSE score – all clients who completed SMMSE			
Base: 349	**Baseline (s.d.)**	**Final (s.d.)**	**Difference**
Mean total score	21.85	21.9	+0.05

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

Changes in the extent of cognitive impairment indicated by total SMMSE scores			
Extent of cognitive impairment (Base: 349)	**Baseline**	**Final**	**Difference**
Severe (total score 0-9)	1%	2%	+1%
Moderate (total score 10-20)	39%	28%	-11% **
Mild (total score 21-24)	24%	39%	+15% **
No impairment potentially (total score 25-30)	36%	30%	-6%

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

Changes in the extent of cognitive impairment in those whose baseline total SMMSE score indicated moderate dementia

Extent of cognitive impairment (Base: 137)	Baseline	Final	Difference
Severe (total score 0-9)	0%	4%	+4%
Moderate (total score 10-20)	100%	58%	-42% **
Mild (total score 21-24)	0%	33%	+33% **
No impairment potentially (total score 25-30)	0%	5%	+5% **

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

Changes in the extent of cognitive impairment in those whose baseline total SMMSE score indicated potentially no impairment

Extent of cognitive impairment (Base: 126)	Baseline	Final	Difference
Severe (total score 0-9)	0%	1%	+1%
Moderate (total score 10-20)	0%	6%	+6% **
Mild (total score 21-24)	0%	28%	+28% **
No impairment potentially (total score 25-30)	100%	66%	-34% **

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

Changes in mean total SMMSE scores by different client groups			
Variable [24] (Base)	Baseline (s.d.)	Final (s.d.)	Difference
Cohort (Base)			
Cohort 1 (61)	20.13 (5.03)	21.03 (5.1)	+0.9
Cohort 2 (123)	21.87 (5.13)	21.53 (5.49)	-0.34
Cohort 3 (165)	22.47 (5.35)	22.5 (.5.9)	+0.03
Delivery mode (Base)			
Face-to-face (312)	21.66 (5.28)	21.59 (5.68)	-0.07
Online (35)	23.43 (5.15)	24.46 (4.67)	+1.03
Type of dementia (Base)			
Alzheimer (113)	20.66 (4.77)	20.49 (5.64)	-0.17
Vascular (42)	20.02 (5.18)	20.74 (5.95)	+0.72
Other types (91)	21.99 (5.48)	22.19 (5.21)	+0.2
Not diagnosed (50)	23.94 (4.93)	23.12 (5.58)	-0.82
Final mean total QOL-AD score (Base)			
Lower than average (126)	21.38 (5.38)	20.75 (5.98)	-0.63
Higher than average (191)	22.38 (5.17)	23.14 (4.92)	+0.76
Baseline SMMSE total score (Base)			
Moderate dementia (137)	16.58 (2.71)	17.66 (4.97)	+1.08 *
Mild dementia (84)	22.61 (1.18)	22.62 (3.67)	+0.01
No impairment (126)	27.33 (1.67)	26.06 (3.87)	-1.27 **
Final SMMSE total score (Base)			
Moderate dementia (99)	17.39 (4.27)	15.55 (2.78)	-1.84 **
Mild dementia (137)	21.85 (4.22)	22.58 (1.75)	+0.73
No impairment (106)	26.27 (3.13)	27.97 (1.33)	+1.7 **

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

Only those variables where there were differences in outcomes between different groups of clients, e.g. those attending face-to-face or online, were included in the table.[24]

4: C-DEMQOL

Changes in mean total and domain C-DEMQOL scores – all clients who completed C-DEMQOL			
Base: 179	Baseline (s.d.)	Final (s.d.)	Difference
Mean total score	94.63 (19.44)	92.63 (18.19)	-2
Personal needs mean score	18.08 (5.56)	17.67 (5.18)	-0.41
Carer wellbeing mean score	17.6 (5.23)	17.33 (5)	-0.27
Carer role / patient–carer relationship	21.84 (4.01)	20.83 (4.03)	-1.01 *
Confidence in the future	17.5 (4.72)	17.22 (4.72)	-0.28
Feeling supported	19.62 (4.91)	19.37 (4.89)	-0.25

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

C-DEMQOL questions where changes were observed between baseline and final data			
Question (Base)	**Baseline**	**Final**	**Difference**
Question 1: How much energy caring is taking (177)			
Very little	10%	5%	-5%
Some	32%	34%	+2%
A considerable amount	40%	38%	-2%
Most of my energy	15%	18%	+3%
All of my energy	3%	5%	+2%
Mean score	3.29 (s.d. 0.96)	3.16 (s.d. 0.93)	-0.13
Question 7: Emotional demands of caring (178)			
Very light	4%	3%	-1%
Quite light	12%	10%	-2%
Moderate	40%	36%	-4%
Quite heavy	29%	37%	+8%
Very heavy	15%	13%	-2%
Mean score	2.61 (s.d. 1.01)	2.53 (s.d. 0.96)	-0.08
Question 13: Coping with demands of caring (179)			
Coped very well	21%	16%	-5%
Coped quite well	35%	26%	-9%
Coped OK	37%	43%	+6%
Coped quite poorly	7%	11%	+4%
Coped very poorly	0%	5%	+5% **
Mean score	3.7 (s.d. 0.88)	3.36 (s.d. 1.03)	-0.34 **
Question 14: Feeling resentful about their role as a carer for a person with dementia (175)			
Not at all	45%	41%	-4%
A little resentful	41%	35%	-6%
Quite resentful	8%	18%	+10% **
Resentful	6%	5%	-1%
Very resentful	1%	1%	None
Mean score	4.22 (s.d. 0.89)	4.1 (s.d. 0.94)	-0.12
Question 16. Relationship with the person they care for in the past 4 weeks (178)			
Very good	29%	25%	-4%
Quite good	42%	38%	-4%
Fair	24%	29%	+5%
Quite poor	4%	8%	+4%
Very poor	1%	1%	None
Mean score	3.93 (s.d. 0.9)	3.79 (s.d. 0.93)	-0.14
Question 17: Feeling appreciated by the person they care for (179)			
Always or almost always	35%	32%	-3%
Often	25%	21%	-4%
Sometimes	25%	25%	None
Once in a while	12%	18%	+6%
Never	3%	4%	+1%
Mean score	3.77 (s.d. 1.14)	3.59 (s.d. 1.23)	-0.18

C-DEMQOL questions where changes were observed between baseline and final data			
Question (Base)	Baseline	Final	Difference
Question 18: Feeling frustration towards the person they care for (174)			
None of the time	15%	12%	-3%
A little of the time	41%	32%	-9%
Sometimes	37%	45%	+8%
Once in a while	7%	9%	+2%
Never	0%	1%	+1%
Mean score	3.63 (s.d. 0.83)	3.45 (s.d. 0.86)	-0.18 *
Question 19: Feelings about meeting care needs in the future (176)			
Feel relaxed	3%	3%	None
Have only a few worries	19%	14%	-5%
Have some worries	43%	39%	-4%
Have significant worries	23%	30%	+7%w
Worry a lot	11%	13%	+2%
Mean score	2.8 (s.d. 0.99)	2.65 (s.d. 0.99)	-0.15
Question 28: Feeling supported by family members (177)			
Completely	30%	28%	-2%
Considerably	27%	28%	+1%
To some extent	26%	21%	-5%
A little	12%	15%	+3%
Not at all	5%	7%	+2%
Mean score	3.65 (s.d. 1.17)	3.55 (s.d. 1.25)	-0.1
Question 29: Feeling supported by friends (176)			
Completely	20%	14%	-6%
Considerably	27%	27%	None
To some extent	33%	30%	-3%
A little	15%	20%	+5%
Not at all	5%	9%	+4%
Mean score	3.42 (s.d. 1.12)	3.17 (s.d. 1.16)	-0.25 *

Statistical significance: * used to show statistically significant difference at 95% confidence interval (CI); ** used to show statistically significant difference at 99% CI. Green denotes statistically significant changes that suggest improvements, red denotes statistically significant changes that suggest worsening / decline.

References

Reference Number	Reference Information	Page Number
1	The following measures were reviewed to help with the process of selecting assessment measures for the evaluation: SMMSE; 6-item cognitive impairment test (6CIT); Addenbrooke's Cognitive Examination-III; MoCA; GP COG (GP assessment of cognition) / Mini-COG; QOL-AD; DEM-QOL; C-DEMQOL; Warwick-Edinburgh wellbeing scale.	8
2	332 staff completed the MCST training across the whole programme.	22
3	145 staff members completed this training across the 3 cohorts.	23
4	By November 2023, 1828 Age UK staff and Network Partner staff and volunteers have completed the training.	24
5	This tally is based on the Age UK MCST partner survey from November 2023.	32
6	The remaining 10 partners had not shared information on whether they were continuing their MCST service at the time of writing the final evaluation report.	32
7	Kahle-Wrobleski K, Ye W, Henley D, Hake AM, Siemers E, Chen YF, Liu-Seifert H. Assessing quality of life in Alzheimer's disease: Implications for clinical trials. Alzheimers Dement (Amst). 2016 Dec 13;6:82-90. doi: 10.1016/j.dadm.2016.11.004. PMID: 28229126; PMCID: PMC5312555.	34
8	Meeuwsen EJ, Melis RJ, Van Der Aa GC, Golüke-Willemse GA, De Leest BJ, Van Raak FH, Schölzel-Dorenbos CJ, Verheijen DC, Verhey FR, Visser MC, Wolfs CA, Adang EM, Olde Rikkert MG. Effectiveness of dementia follow-up care by memory clinics or general practitioners: randomised controlled trial. BMJ. 2012 May 15; 344:e3086. doi: 10.1136/bmj.e3086. PMID: 22589500; PMCID: PMC3352696.	34
9	Kahle-Wrobleski K, Ye W, Henley D, Hake AM, Siemers E, Chen YF, Liu-Seifert H. Assessing quality of life in Alzheimer's disease: Implications for clinical trials.	34
10	Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, Orrell M. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. Br J Psychiatry. 2003 Sep;183:248-54. doi: 10.1192/bjp.183.3.248. PMID: 12948999.; Orrell M, Aguirre E, Spector A, Hoare Z, Woods RT, Streater A, Donovan H, Hoe J, Knapp M, Whitaker C, Russell I. Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. Br J Psychiatry. 2014 Jun;204(6):454-61. doi: 10.1192/bjp.bp.113.137414. Epub 2014 Mar 27. PMID: 24676963.	34
11	Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, Orrell M. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial.	34
12	Orrell M, Aguirre E, Spector A, Hoare Z, Woods RT, Streater A, Donovan H, Hoe J, Knapp M, Whitaker C, Russell I. Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial.	34

Reference Number	Reference Information	Page Number
13	Both of these studies are relevant to the evaluation of Age UK's MCST programme. Although the first study examined the impact of CST rather than MCST, it is relevant as most of Age UK's MCST clients had no prior CST so the MCST programme was their entry into CST (255 vs 78 who attended CST beforehand). Therefore, their experience is bound to have some similarities to that of CST participants, for whom that is a starting cognitive stimulation intervention.	34
14	Various studies found that while the mean QOL-AD score changed little over time, there were many and significant changes in total QOL-AD scores for individual older people within those groups being studied. Hoe et al. (2009) therefore stressed the importance of analysing changes in individuals' QOL-AD scores too, in addition to looking at mean scores.	35
15	As the base for cohort 1 was too small (25), it would not be suitable to compare changes in mean scores by cohort in this instance.	35
16	Akpınar Söylemez B, Küçükgüçlü Ö, Akyol MA, Işık AT. Quality of life and factors affecting it in patients with Alzheimer's disease: a cross-sectional study. Health Qual Life Outcomes. 2020 Sep 10;18(1):304.	35
17	Quantitative findings for online MCST should be treated with caution, however, due to the small sample size (No = 36) and more future research is needed to understand the impact of online MCST quantitatively.	43
18	There is no established minimum important difference for C-DEMQOL, making it challenging to understand the significance of any difference in scores.	47
19	Cohort 1 partners started delivering the programme before the evaluation started and C-DEMQOL was not in place as a measure at the time. Following desk research on potential measures to use, it was decided that C-DEMQOL would be used to assess any changes in the quality of life of carers. The questionnaire was used in cohorts 2 and 3.	47
20	Three other versions of this discussion guide were used in the evaluation: 1) the 3-month fieldwork point version which was largely the same but also reminded clients and carers that they would be re-contacted for follow-up interviews about 3 months later; 2) client re-contact discussion guide (which was used for follow-up interviews, included similar questions about their experience of the programme and the impact, but was shorter; 3) carer re-contact discussion guide (which was used for follow-up interviews, included similar questions about their observations about the programme and its impact, but was shorter).	68
21	Note for moderator – this training did not need to be attended by the project leads so it could have been that other members of staff attended rather than the ones we're interviewing.	74

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