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

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Prepared for: Age UK

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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: Executive summary

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. CST usually runs for 7-14 weeks and offers a programme of themed and structured activities. Maintenance Cognitive Stimulation Therapy (MCST) was developed to maintain the positive benefits of CST through a longer-term programme.

Given the benefits that MCST can bring to people living with mild to moderate dementia and mild cognitive impairment, as well as 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 MCST services.

With generous funding from the Association of British Insurers' (ABI) *'Covid-19 Support Fund',* Age UK have been able to do that by setting up 157 new MCST groups across the Age UK network. The majority of these groups were delivered face-to-face (133), whereas 24 were delivered online. Out of 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 AND METHODOLOGY

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 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 was used to assess any changes in clients' quality of life and cognition following the programme, as well as any difference to carers' quality of life. The assessment measures used in the evaluation included: The Standardised Mini-Mental State Examination (SMMSE)[1], Quality of Life in Alzheimer's Disease (QOL-AD)[2] and C-DEMQOL (a measure of carer quality of life for carers of people living with dementia).[3]

Qualitative research was carried out with MCST clients, carers and staff to understand their experiences of the programme and its perceived impact. The evaluation involved 200 respondents (67 clients, 58 carers and 75 MCST staff) and used mixed qualitative methods, including:

- 56 x pair and 13 x single depth interviews with clients and carers;
- 46 x follow-up individual interviews with clients and carers;
- 13 x group discussions and 19 x pair or individual depth interviews with staff.

Desk research was used to inform the research design and instruments and review existing evidence and information on CST and MCST.

Expert interviews were conducted to complement other data and evidence and understand better how MCST fits within the broader landscape of dementia support services.

2.3: SUCCESSES OF THE MCST PROGRAMME

The evaluation found that the MCST programme achieved its first intended outcome to improve wellbeing for people living with mild to moderate dementia, and improve, or slow the decline, of their cognitive abilities:

- 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. Qualitative research further suggested that clients, carers and staff felt that this improvement was significant. Key benefits clients experienced which contributed to better quality of life included: social re-integration through the MCST programme; improved mood; learning how to cope with dementia; and improved self-esteem, motivation, independence, and orientation.
- In addition, comparisons between clients' baseline and final mean total SMMSE scores 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 suggests the protective character of MCST in slowing down cognitive decline.
- Qualitative research found that clients, carers and staff observed a range of 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, having more confidence to do certain things for themselves. Respondents were less certain that the intervention improved clients' memory, although some did see improvements in this respect too.

The evaluation findings above add further evidence to the existing body of research into the benefits and effectiveness of MCST in improving quality of life in people living with dementia and improving or maintaining their cognitive skills.

The MCST programme itself was seen as a big success by clients, carers and staff involved. The principles of cognitive stimulation, the programme structure and activities were all perceived to work extremely well to engage older people living with dementia and support them to achieve a range of cognitive and wellbeing benefits. Some key factors contributing to its effectiveness were identified as: therapeutic aims and focus of MCST; varied activities of suitable difficulty; structured but tailored approach; regularity and continuity of sessions; small groups that foster social relationships and sharing of experiences; supportive staff who are skilled at working with people living with dementia.

The programme also achieved its outcome with regards to staff as they felt that the training and experience of delivering the programme equipped them with the knowledge, skills and confidence needed to deliver MCST. More broadly, the programme succeeded in growing MCST provision across the Age UK Network. Following the initial, funded period of 24 weeks, 59% of Network Partners involved in the programme decided to carry on with their MCST groups and make it part of their dementia support offer. As of November 2023, at least 83 MCST groups were being delivered across the network, continuing beyond the funded programme.

Some Network Partners have also succeeded at expanding the MCST programme to adapt it to different groups and modes of delivery. Specifically, staff have developed materials and approaches to adapt MCST to online delivery or make it more culturally diverse. Their experiences and learnings will be a useful contribution to the future MCST practice.

2.4: CHALLENGES OF THE MCST PROGRAMME

The evaluation suggests that client referrals and recruitment for the MCST programme can be challenging and take some time to build the trust in, and awareness of, the programme. Low social confidence, stigma attached to dementia and denial all created challenges for recruiting people living with mild to moderate dementia. In addition, some groups were particularly underrepresented as clients in the programme, for example, ethnic minority groups; or had additional barriers, for example, housebound people living with dementia. The evaluation highlighted steps that can be taken to support client recruitment:

- Offering taster sessions to build client confidence;
- Stressing the social and cognitive benefits of MCST;
- Raising awareness of MCST among carers and people living with mild to moderate dementia, as well as health professionals in areas where CST is not offered through the NHS;
- Building local relationships and networks specific to dementia support that can be activated for MCST recruitment;
- Offering online MCST to those who cannot access face-to-face sessions;
- Future MCST services would also need to improve their reach among some under-represented groups, most notably, people living with dementia from ethnic minority groups.

The evaluation also highlighted some challenges in the programme delivery. The main challenges included:

- Adapting the programme to online delivery or to make it more culturally diverse, as staff found there was limited guidance on how to do that;
- Managing differences within MCST groups, where they included people at different stages of dementia or clients who were a minority in their group, for example, based on gender, age or ethnicity;
- Supporting clients to be able to take part in the programme, which was sometimes time-intensive for staff or required additional resource during the sessions;
- Managing oscillations in MCST group size, due to absences or clients leaving the programme because of ill-health or moving into care.

The evaluation further suggested that it may be difficult for the MCST programme to improve carers' quality of life significantly, even if it did provide important benefits to them. Carers interviewed for the evaluation reported the programme gave them some respite and they felt they benefitted in terms of their mood, wellbeing and quality of life, as well as through peer support. Quantitative data, however, suggested a slight worsening in carers' quality of life over time. **The evaluation, therefore, indicated that the MCST programmes improved carers' wellbeing to some extent, but that carers' quality of life still deteriorated over time due to the demands of caring for someone living with dementia.**

The mixed results concerning the impact of the MCST programme on carers may be due to a lack of consistent approach to carer support within the programme. Most Network Partners did not specifically target carers through additional carer support whereas a minority offered targeted carer support groups. In the future, such groups could potentially help carers cope better with the demands of caring through helping them access other available support and providing emotional and psychological support.

Making MCST financially feasible on a longer-term basis was recognised as a major challenge by Age UK Network Partners. While many offered the initial 24 weeks for free, most felt they would need to introduce a small fee to continue beyond the funded period. However, staff also recognised that fees would not cover the costs of MCST and that they would need to access additional funding to continue. Not being able to access this funding was cited as a main reason for not continuing with MCST where groups stopped after the initial programme.

2.5: COMPARISON BETWEEN FACE-TO-FACE AND ONLINE MCST

The evaluation found that both face-to-face and online MCST clients enjoyed the programme and 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.

2.6: HOW MCST IS DIFFERENT FROM OTHER DEMENTIA SUPPORT

The evaluation found that CST and MCST were perceived to be different from other dementia support. The following features of MCST were seen as different compared to other support available:

- Therapeutic aims – clear and explicit focus of MCST on improving cognition;
- Evidence-based approach that is effective in dementia, making MCST more clinical than other support;
- Standardised training and manual supporting diverse staff to deliver the MCST programme in a consistent way;
- Varied activities catering for diverse interests that can reach a wide 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 living with mild to moderate dementia, which many felt addressed a major a gap in dementia support provision (which is likely to remain an issue in areas where CST/MCST is not available).

2.7: FUTURE OF AGE UK'S MCST SERVICES

The evaluation suggested MCST was perceived as a *'gateway'* service that should be accessed prior to or immediately after the diagnosis (or following CST, where this was available). In this context, CST and MCST programmes were seen as key services for providing support to those with mild to moderate dementia, whereas day centres were central to supporting those with more advanced dementia. Clients, carers, 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. The evaluation identified different models for continuing MCST beyond the initial 24 weeks, including carrying on in the same vein with a structured programme, switching to a less structured peer support group, and basing day centre activities on MCST principles but in a less formal way.

There was a strong belief that as an evidence-based effective intervention, CST/MCST should be a mainstream, statutory service that should be available to all people living with dementia as post-diagnosis support. 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. As mentioned, most partners thought they would need to charge a fee and have additional funding to make MCST financially viable.

References

Reference Number	Reference Information	Page Number
1	For the SMMSE questionnaire see: **https://www.ihacpa.gov.au/sites/default/files/2022-08/smmse-tool-v2.pdf**	**6**
2	For the QOL-AD questionnaire see: **https://www.cogsclub.org.uk/professionals/files/QOL-AD.pdf**	**6**
3	For the C-DEMQOL questionnaire see: **https://www.bsms.ac.uk/_pdf/cds/c-demqol-researcher-administered-final.pdf**	**6**

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