

# Cognitive stimulation therapy for dementia: Provision in National Health Service settings in England, Scotland and Wales

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## Abstract

**Objectives:** Cognitive stimulation therapy (CST) is a brief, non-pharmacological intervention for people with dementia, with an established evidence base for improving cognition and quality of life. It is widely implemented in National Health Service (NHS) settings, but little is known about its naturalistic use. The aim of this survey was to identify and explore inclusion criteria, dose and quality of CST across services in Great Britain (England, Scotland and Wales).

**Methods:** All NHS memory clinics and services for people with dementia were contacted and asked to complete a mixed methods online survey on CST delivery in their service. Questions were centred on who provided CST, who received CST, the dose of CST and any outcomes that were routinely measured.

**Results:** A total of 57/186 services responded, giving a response rate of 30.7%. While the majority reported offering CST (87.7%), there was variability in how this was delivered. Differing inclusion criteria included the use of varying cognitive and behavioural outcome measures, and CST was reported as being offered once and twice weekly. Services also differed in how they evaluated the quality of CST and how this evidence was incorporated for future sessions.

**Conclusion:** While there was a low response rate, this survey indicates that there is significant

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variability in how CST is used in clinical practice, with many trusts not adhering to the evidence base. To ensure that people with dementia are consistently offered evidence-based, high-quality CST across NHS settings, further standardisation of inclusion criteria, dose and outcomes is needed.

## Keywords

psychosocial, Alzheimer, implementation, memory clinic, cognition

## Introduction

Cognitive stimulation therapy (CST) is a brief, manualised psychosocial therapy for people with Alzheimer's disease and other dementias (Aguirre et al., 2011; Spector et al., 2006; Yates et al., 2014). While other generalised programmes exist, manualised CST as developed in the United Kingdom has a consistent evidence base for improving cognition and quality of life (Lobbia et al., 2018; Spector et al., 2010, 2003). Evidence also suggests that CST may enhance confidence and motivation (Spector et al., 2011), and it has been consistently recommended for use by the National Institute for Health and Care Excellence since 2006 (NICE, 2006, 2018).

CST was designed to be a low-cost intervention that could be delivered by professionals from a range of backgrounds, and it has been suggested as more cost-effective than treatment as usual (Knapp et al., 2006). No educational qualification criteria are listed for potential facilitators, but it is suggested that they have some experience of working with people living with dementia (Spector et al., 2006) and attend a 1-day training session.

As delivered according to the evidence base, group CST consists of 14, 45-minute sessions delivered twice weekly over seven weeks, giving a total intervention time of 10.5 hours. Sessions are based on eight fundamental principles which include mental stimulation, promoting new ideas, thoughts and associations, a focus on opinions rather than facts, maximising the potential of people with dementia, respect and person-centredness. Other formats have recently been evaluated and include maintenance CST (MCST) delivered straight after the initial 14 sessions. Evidence suggests that MCST also improves quality of life and can help to improve the cognition of those taking anticholinesterase inhibitors (Orrell et al., 2014). Most recently, individualised CST (iCST) delivered by family carers to their relative or friend with dementia (Orrell et al., 2017) was evaluated. Whilst this programme improved the relationship between people with dementia and their family carers, as well as carers' quality of life, there were no significant changes in cognition and quality of life.

Both the robust evidence base and ease of use have contributed to extensive use of CST, with a recent audit suggesting 90% of memory clinics offer access to group CST (Royal College of Psychiatrists, 2016). This suggests widespread implementation in the UK National Health Service (NHS). However, how CST is delivered in a naturalistic setting can vary widely, with significant differences reported in training sessions (Streater et al., 2017). This suggests that CST may not always be delivered in ways that are consistent with the underlying evidence base. This has the potential to significantly impact the quality of CST for people with dementia, but the exact extent of this variability is unknown. Thus, the aims of this survey were to (1) identify prevalence of CST provision in services for older adults with dementia in Great Britain, (2) explore differences in CST delivery including the inclusion criteria and dose, (3) explore how the quality of CST is maintained and 4) identify common outcomes and make recommendations for standardisation.

## Methods

### *Design*

A mixed method, cross-sectional survey was conducted to obtain in-depth information about provision of CST within NHS dementia services across England, Scotland and Wales.

### *Recruitment*

Memory clinics in Great Britain (England, Scotland and Wales) were identified via the Memory Service National Accreditation Programme (MSNAP), and internet searches were conducted to identify further NHS services that specified that they offered support to people with mild to moderate dementia or offered 'cognitive stimulation'. Internet searches included key words such as 'NHS', 'Memory', 'Cognitive stimulation', 'Dementia', 'group interventions' and 'individual interventions'. Information was retrieved from NHS Trust websites and NHS Choices website resulting in a list of 186 services across 64 NHS trusts. No contact information was traceable for two services. Identified services included memory clinics, day centres and hospitals.

### *Procedure*

Services were initially approached using telephone calls or emails. If the first point of contact was a telephone call, then the nature of the call was explained, and a request was made for the call to be directed to the professional who would be most likely to act as a respondent for the survey. This respondent was a member of staff who currently administered or supervised CST provision for their organisation and could include psychologists, occupational therapists, support workers, nurses or other allied professionals. Once identified, the respondent was invited to take part in the survey via an email, which contained the study link. Email invites were sent via the MSNAP discussion platform and Contact Help Advice Information Network; an online NHS network. These invites included the online link and the contact details of the researcher, whom participants were advised to contact should they have any questions preceding, during or following completion of the survey. Dementia services that did not offer CST were encouraged to complete the initial questions in the survey. Ethical permissions were obtained from University College London ethics committee, and all participants were presented with an information sheet and required to provide informed consent. The survey was not available to view until this was given.

### *Survey*

The questionnaire was developed iteratively by the authors and in consultation with the MSNAP team. Initially, draft questions were generated and reviewed for relevance and clarity by the study team. Small changes were subsequently made to item wording. The final survey consisted of 45 possible closed- and open-ended questions on the provision and delivery of CST in each setting, yielding quantitative and qualitative data. The number of questions presented differed dependent on selected answers. For instance, if a service did not provide CST, the respondent was only presented with a maximum of seven questions. These seven questions pertained to whether CST had been offered in the past and why it was no longer provided. The survey was administered and stored online using Qualtrics software. Data collected included inclusion and exclusion criteria, dose, job roles of CST facilitators and supervisors, how quality was measured and routine outcome measurement. Participants

were asked to provide their job title and the NHS trust they worked for, but no identifiable information was collected.

## *Analysis*

All survey responses were downloaded into Excel for data cleaning. Incomplete survey responses were deleted on a case-wise basis, and completed initial questions were saved separately. Quantitative data were analysed using frequency and descriptive statistics in the Statistical Package for Social Sciences. Thematic analysis (Braun & Clarke, 2006) was used for qualitative data to identify themes and sub-themes for open-ended questions. All responses were coded; patterns within the response were identified from every response. The final themes and sub-themes were developed from the initial coding.

## **Results**

### *Response rate*

Initially 41 completed surveys were returned from 186 services. A further 100 telephone calls were made, and 88 emails were sent to non-responders, resulting in the submission of an additional 16 surveys, giving a total of 57 and response rate of 30.7%. However, not all participants completed all sections of the survey and some gave uninterpretable responses. As such, the total sample size (*n*) differs by survey item.

### *Services offering CST*

A majority reported that their service offered manualised CST (87.7%, 50/57), as described in the introduction, whilst seven reported no CST provision. Of the services that did not directly provide CST, two reported CST via external provision (28.6%, 2/7) and five reported no external provision (71.4%, 5/7). Of these seven services that had never directly offered CST, six services had never provided CST (85.7%, 6/7), and one service reported that they had discontinued CST having previously offered it for 5 years (14.3%, 1/7). CST was discontinued in this service after a managerial review resulted in a move to support third sector organisations to provide CST instead.

### *Inclusion criteria for CST*

Inclusion criteria at a participant level varied across services. In data obtained from 50 respondents, four themes were identified as part of inclusion criteria listed by services: (1) diagnosis, (2) ability, (3) internal factors and (4) external factors (Table 1).

*Themes 1 and 2: Diagnosis and ability.* There was a predominant focus on clinical diagnosis, cognitive impairment and the use of cut-offs on formal measures of cognition. For example one exclusion criterion was an Addenbrooke's Cognitive Examination Revised (ACE-R) score of <60. There were also instances where people with mild cognitive impairment were included. However, service user ability occurred the most out of four themes. This included hearing and visual impairments as well as mobility, communication and cognitive ability. A number of services also excluded service users if they were deemed to lack capacity to provide informed consent.

**Table 1.** Inclusion and exclusion criteria for provision ( $n = 50/57$ ).

Theme	Definition	Occurrence	Sub-theme	Example	
				Inclusion Criterion	Exclusion criterion
Diagnosis	Professional assessment of impairment and/or clinical diagnosis	47	Diagnosis Degree of impairment Use of cognition measures	Formal diagnosis of dementia Mild to moderate dementia or mild cognitive impairment Mini-Mental State Examination score of 14–22	Non-dementia diagnosis. No cognitive impairment Moderate to severe dementia presentation Addenbrooke's Cognitive Exam revised score <60
Ability	Physical or cognitive capability to access information provided by the training or the manual	49	Visual/auditory Physical Cognitive Communication	No significant hearing or visual impairment that would impact on group engagement Able to participate/able to sit for the duration of the group Patient has capacity to make decisions about the activities that he/she would like to engage in Ability to communicate in a group setting	Auditory or visual impairments that are not resolved with aids (e.g. hearing aids or glasses) Co-morbid physical health problems that would affect attending weekly sessions Lacks capacity to consent to the group Unable to communicate well enough to participate in the group
Internal factors	Individual characteristics determined by the service providing the intervention	28	Behaviour Motivation Independence	Able to stay in the group setting for 1 hour Motivation to engage in the group Independent personal care	High levels of agitation or distress Does not consent to the group Housebound/unable to attend clinic

*(continued)*

**Table 1.** (continued)

Theme	Definition	Occurrence	Sub-theme	Example	
				Inclusion Criterion	Exclusion criterion
External factors	Circumstances extrinsic to dementia diagnosis	10	Transport Prior support Staff/service	Able to travel to clinic (education course for informal carers runs concurrently to facilitate this) Has completed newly diagnosed group Participants require an allocated care coordinator for length of sessions	Inability to travel Attending day services No cluster, or clusters other than 18/19*

\*Clusters 18 and 19 refer to people classified as having additional needs requiring shortened and simplified activities

*Theme 3: Internal factors.* Internal factors were specifically related to the person with dementia's characteristics and their ability to participate in CST activities. Behaviour, and most commonly agitated behaviour, was included in a number of services' exclusion criteria. Commitment and motivation were also prominent with service users who were unable or unwilling to commit to a full CST intervention were excluded. Finally, the sub-theme of 'independence' was identified, with residing in a nursing or residential care facility used as an exclusion criterion. Service users were also required to be capable of attending to their own personal care during sessions in some services.

*Theme 4: External factors.* External factors were identified as criteria that were not under the control of service users. Most commonly, this was related to transport. One service appeared to provide this transport as the criterion was listed as 'be able to use transport facilities provided'. However, no other instances of transport being provided were identified, and participants were excluded if they were unable to travel to and from the service for CST sessions. Another sub-theme, entitled prior support, was used for participants for whom prior attendance at previous groups was a requirement for acceptance to CST. Such groups were commonly newly diagnosed support groups. The final sub-theme was 'staff or service factors', where services listed additional criteria such as the provision of an allocated care coordinator for service users.

### CST dose

CST provision varied greatly across services with regard to duration, group size (Table 2), frequency, total sessions provided and session tailoring. For frequency, 51% (25/49) services offered CST twice weekly and 42.9% (21/49) offered weekly sessions. Of the 6.1% (3/49) who selected 'other', one provided 'three cohorts' a week with no further details on frequency, one stated they ran sessions once a week but only for 4 months of the year. The final response in this category noted the frequency

**Table 2.** Variation in cognitive stimulation therapy provision across Great Britain.

Detail	N	Mean	SD	Range
Session Length (minutes)	49	90	33.1	45–210
Average group size	44	7.6	2.4	2–12
Minimum group size	37	4.4	2.5	2–12
Maximum group size	36	9.6	1.4	6–12
Groups facilitated (per year)	31	10	16.1	1–90

as ‘between 0 and 10’. While it is likely this referred to cohorts rather than weekly frequency of the same CST group, a definitive statement cannot be made.

Of the 45 participants who provided interpretable data, 44.4% (20/45) offered the full 14 sessions. Many services 77.8% (35/45) did not offer extended or MCST sessions. However, 31% (14/45) of responders reported that they offered further sessions when needed. Of the services that provided CST sessions (50/57), 74.1% (22/57) offered different groups for differing levels of ability/severity of impairment. However, of these services, 59.3% (16/57) reported that they did not specifically adapt or change the provision of CST for different ability across service users. Further to this, 66.7% (38/57) of services did not offer further group options such as gender specific groups for variable levels of English. A majority of carers were also offered concurrent support 68.4% (39/57), whilst 17.5% (10/57) services reported they offered no support or services to carers or family members of CST participants.

### *CST facilitators*

Each service had between two and seven members of staff who were currently responsible for facilitating CST sessions ( $n = 30$ ,  $M = 3.4$ ,  $SD = 1.48$ ). However, 21 results for this particular question were uninterpretable and two respondents did not answer. Examples of uninterpretable answers included a string of digits or text, potentially entered to allow responders to move on to the next question without answering. As respondents were able to select all applicable professionals involved in facilitating CST, there was a total of 129 professions listed, with CST facilitators most commonly support workers 25.6% (33/129) or occupational therapists (24%, 31/129; [Table 3](#)). Of the 49 services that provided data for this item, CST facilitators were offered clinical supervision in 43 services, whilst six were offered no clinical supervision. Supervision was most commonly provided on a monthly basis 48.8% (21/43) but was also reported to be offered weekly 16.3% (7/43), ad hoc 11.6% (5/43), after each session 6.98% (3/43), every 6 weeks 6.98% (3/43) or quarterly 6.98% (3/43). One responder noted that they were unsure how often supervision was offered. As professions of supervisors could be listed, a total of 51 responses were recorded. Supervisors were most likely to be psychologists 29.4% (15/51) or occupational therapists 19.6% (10/51). Less commonly, CST facilitators were supervised by assistant psychologists 1.96% (1/51), clinical leads 1.96% (1/51), line managers 1.96% (1/51), another team member 1.96% (1/51) or trainee psychologists 1.96% (1/51; [Table 3](#)).

### *CST quality*

Three themes were identified for assessing and monitoring the quality of CST: external, internal and service user. External consisted of three sub-themes: CST manual, external training and literature. CST facilitators noted that, to ensure the quality of CST remained, they regularly referred to and continued to use the CST manual. In many cases, this was the only way the service ensured the

**Table 3.** Professions of CST facilitators and supervisors.

		<i>n</i>	%
Professions of CST facilitators	Support Worker	33	25.6
	Occupational therapist	31	24
	Nurse	20	15.5
	Clinical psychologist	14	10.9
	Healthcare assistant	10	7.8
	Other	21	16.3
	Missing	2	4.4
Professions of CST supervisors	Psychologist	15	29.4
	Occupational therapist	10	19.6
	Team manager	7	13.7
	Team lead	5	9.8
	Staff nurse	3	5.9
	Nurse practitioner	2	3.9
	Team member	1	3.6
	Trainee psychologist	1	3.6
Other	7	13.7	

CST: cognitive stimulation therapy.

standard of provision remained high: *'We adhere to the manual'*. External training referred to the undertaking of external training on CST. Staff facilitating CST sessions noted that they had attended the initial CST training for facilitators. However, responses also indicated that one member of the team had completed the training and relayed the information back: *'Someone from the day hospital went on the training and has worked with the psychologist to deliver groups'*. Finally, for the third theme, services also noted that they *'keep updated on Evidence Based Practice'*.

The second theme referred to actions undertaken by services that aimed to ensure quality of provision was maintained. The first sub-theme was supervision, which was prominent across the trusts. A number of services included observational supervision: *'each staff member is observed in their ability to facilitate the group prior to being the lead facilitator'*. Further to this, services also reported: *'evaluating each session as a team'*. The sub-theme audit described conducting regular audits in order to provide a continuous high standard of care provision. The final and least common theme was service users, which included the use of feedback forms and outcome measures.

### Outcome monitoring

Of 49 respondents who provided data, 46 reported monitoring outcomes associated with CST. Outcomes monitored consisted of quality of life 67.4% (31/46), quality of provision 58.7% (27/46) and cognition 56.5% (26/46). However, each of these outcomes was measured in varying formats across services. Quality of life was stated to have been measured using formal outcome measures, feedback forms and qualitative interviews. Similarly, cognition was evaluated using outcome measures, by observation, using feedback forms from participants and as part of formal qualitative interviews. Quality of provision was evaluated using audits and observation of sessions. For cognition, outcome measures used were the Mini-Mental State Examination (MMSE), the Montreal Cognitive Assessment (MoCA) and the Addenbrookes Cognitive Examination (ACE-III). However, no respondents gave details of the specific quality of life measures used.

## Discussion

CST is an evidence-based intervention for dementia that is widely implemented in NHS settings. This mixed methods national survey evidences that, whilst provision of CST is high, there is significant variability in its implementation and use across NHS settings Great Britain. Whilst the response rate of 57 complete responses from 186 services was low, these variations are significant and are likely to impact on both who is offered CST and how effective it is for them. Thus, there may be a need to adopt standardised criteria for the provision and delivery of CST in NHS settings.

Variation in inclusion and exclusion criteria indicated that access to CST differed across services. Further, it was unclear how these criteria were applied and could be based on objective outcome measures or subjective opinions of staff. Some exclusion criteria, such as lacking capacity to consent, were common across services. For those that did not specify this criterion, it was unclear if there were provisions in place to ensure that people with dementia who lacked capacity were still offered appropriate interventions such as CST. Further to this, agitation was commonly listed as an exclusion criterion, but it is unclear how this was applied in practice. For example it was not clear whether this information was gathered from care notes, from carers or from formal assessments by professionals. Notably, participants could also be excluded from CST for deficits in communication, despite evidence suggesting CST may improve communication skills for people with dementia (Spector et al., 2003, 2010, 2011).

CST dose was also rarely in accordance with the evidence base, with 20/50 services offering sessions once a week over 14 weeks instead of twice weekly for seven weeks. Session length varied from under 45 minutes per session to two-hour sessions. It was unclear why the frequency and session length were changed for these services but may have been due to practical implementation issues including staff availability. This has important implications as the evidence base suggests weekly CST might not be as effective (Cove et al., 2014). The majority of services offered the full 14 sessions of CST, but some offered considerably less. For example 2.2% (1/45) offered only one session and 8.9% (4/45) offered two sessions. Further, despite evidence suggesting MCST can also be effective (D'Amico et al., 2015; Orrell et al., 2014; Streater et al., 2012), a large proportion of respondents offered no further sessions or continuation of CST after the initial group had ended.

CST was designed to be delivered with minimal training requirements and specialist knowledge. Evidence from this survey suggests that in keeping with the original evidence base, CST was successfully delivered by a range of professionals including support workers and clinical psychologists. However, it was more common for only one of the facilitators to attend formal training on CST, with feedback from the trained facilitator and the manual used to equip co-facilitators. This may dilute the effects of training if information is not passed on effectively but does have the advantage of enabling a cascade training model thereby reducing training costs. Clinical supervision, an important means of ensuring the therapeutic value of sessions, was used variably from a low of quarterly to a high of weekly.

The benefits of CST in clinical practice were hard to quantify as methods used varied considerably. Evaluation of benefits to people with dementia could consist of observation, feedback from recipients or the use of standardised outcome measures, and it was unclear how this data were used in practice. Differing outcomes may be based on usual practice at each NHS site but limits the degree to which cross-service comparisons can be made. The use of different outcome measures were identified for cognition, whilst the specific measures used for quality of life were not detailed.

### *Methodological problems and limitations*

The response rate for this survey was low, and consequently, responses here may not have been representative of all CST provision across England, Scotland and Wales. Whilst recontacting services did improve the response rate, many memory clinics and other services did not provide data. It is unclear why the response rate was low and could be due to staff availability and resources or perceived non-importance of the survey. To increase the response rate in future, it may be advisable to incentivise participation or liaise with management to ensure staff are granted reasonable time and resources to participate.

The survey was mixed methods with open-ended questions. This was designed to capture the variability between services but led to some uninterpretable responses. For example some responses contained a random string of digits, potentially allowing the responder to move on to the next question without giving a response.

### *Implications for practice and future research*

Differing methods for collecting and assessing outcomes associated with CST indicates a potential need to determine standardised inclusion criteria, dose and a core outcome set (COS). The COS is an agreed minimum set of outcomes that should be measured in all clinical trials (Clarke, 2007). Whilst clinical trials undoubtedly differ from clinical practice, the COS is a methodologically robust way of ensuring that the effectiveness of CST is assessed reliably across services. The evidence base for CST was established using the ADAS-Cog (Rosen et al., 1984) and the Quality of Life in Alzheimer's Disease Scale (Logsdon et al., 1999; Spector et al., 2003). Whilst the Alzheimer's Disease Assessment Schedule-Cognitive Subscale (ADAS-Cog) may not be suitable for clinical practice, its comparison with other more commonly used measures of cognition in further formal research studies of CST could support the identification of a suitable cognition outcome for both. Standardisation of outcomes may lead to a minimum dataset of the effectiveness of CST as used in practice, with other measures added as required by services. Such data can subsequently be used to inform practice, where staff use results to inform future facilitation. This will help to ensure that CST delivery remains of a high standard and ensure that people with dementia always receive high-quality, evidence-based CST. Further, an anonymised dataset could be created from these data to facilitate comparisons in the effectiveness of CST across services.

Data collected here only pertain to NHS settings. Whilst implementation may be high here, the degree to which CST is used and the differences in provision in other settings are unclear. Therefore, this survey could be expanded upon and repeated in the private sector to include care homes and private clinics. An evaluation of any differences in use and provision in either setting may further inform implementation in the other.

### **Conclusion**

Whilst the implementation of CST is high in NHS settings, in practice, it is delivered variably. Across England, Scotland and Wales, there were documented differences in whom CST is offered, the dose of what they were offered and the outcomes routinely measured. This variability precludes an analysis of how effective CST is, as delivered as part of care. It is recommended that standardised criteria and outcomes are adopted to ensure that CST is both delivered to a high standard and that people with dementia consistently receive high-quality, evidence-based interventions.

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