The Adaptation of Group Cognitive Stimulation Therapy for People With Intellectual Disabilities who Have Developed Dementia

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Thesis Declaration Form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Part 1 of this thesis is a systematic review exploring the views and experiences of dementia from the perspective of people with intellectual disabilities with and without co-occurring dementia as well as exploring the qualitative methodologies employed to include people with intellectual disabilities with dementia in qualitative research. A thematic synthesis of 9 studies was carried out in this review.

Part 2 was originally due to be a qualitative investigation of the acceptability and feasibility of CST for people with intellectual disabilities and dementia (CSTIDD). However due to significant delays with getting site approval, recruitment challenges and logistical difficulties with running the groups there were limited participants for interview. The focus of Part 2 was therefore shifted to the development of the adapted intervention through a series of stages of input from stakeholders, including one pilot group of CSTIDD. The final adapted supplement for CSTIDD is reported.

Part 3 is a critical appraisal which reflects on the process of carrying out Part 1 and Part 2. This includes reflecting on my personal influence on the research, the process of reviewing the qualitative data in Part 1 and some of the challenges of Part 2 that led to the change in focus.

Terminology

Although the term “learning disability” is widely used in UK clinical services, “intellectual disability” is more widely used in UK and global research, therefore this terminology will be used throughout.

Impact Statement

Impact of Part 1

In Part 1 of this thesis, a synthesis of the views and experiences of dementia from the perspective of people with intellectual disabilities is presented. This has practical implications for clinical practice, highlighting the need to support the sense of self and wellbeing of a person with intellectual disabilities and dementia through to facilitating choice, competence and relational connection. Some of the ways carers can support these aspects is highlighted. Recommendations are also made about the training of care staff in the areas highlighted by the review.

Part 1 also details the different methodologies used to date when including participants with intellectual disabilities and dementia in qualitative research. The results importantly highlight that qualitative research is feasible in this population, which should encourage researchers to include this population in future research. There are, however, understandable challenges to this so this review also helpfully identifies a number of adaptations that have been used. This is invaluable to enable the perspectives of people with intellectual disabilities and dementia to be included in future research. One key recommendation from part 1 is to use more visual methodologies. This fed into part 2 of this thesis which includes a qualitative interview with a participant with intellectual disabilities and dementia using a Talking Mat.

Impact of Part 2

In Part 2 of this thesis, the process of the adaptation of CST for intellectual disabilities is described and the final supplement presented. The results of this paper have already been disseminated to group facilitators in a wider feasibility randomised controlled trial to examine it’s acceptability and feasibility. This will be beneficial to future research to have a standardised manual to be able to conduct further research to investigate efficacy. This is also beneficial for the clinical care of people with intellectual disabilities and dementia to be working towards an evidence-based intervention for this population.

Part 2 also builds on the evidence of Part 1 demonstrating that people with intellectual disabilities and dementia can be included in qualitative research. It is the first known use of Talking Mats in research with people who have both intellectual disabilities and dementia. Therefore this benefits future research which could use this approach to include the views and experiences of people with intellectual disabilities and dementia.

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Part 1: Literature Review

Views and Experiences of Dementia in Intellectual Disability: A Systematic Review of Qualitative Research

Abstract

Aims

The prevalence of dementia is increasing in the intellectual disability population but there is limited research. This review aimed to explore the views and experiences of dementia from the perspective of people with intellectual disabilities and the ways in which people with intellectual disabilities and dementia have participated in qualitative research.

Methods

Database searches using PsycINFO, Medline, Web of Science as well as reference and citation searches were undertaken to identify qualitative studies that explored the views and experiences of dementia from the perspective of people with intellectual disabilities. A thematic synthesis approach was used to review qualitative data and methodologies used in the included studies were reviewed.

Results

Nine studies were identified. Findings highlighted how people with intellectual disabilities view and experience loss and transition associated with dementia, maintenance of a sense of self through choice, relational connection and competence is important, and support from others counteracts loss. Studies used interview and observation based approaches with a range of adaptations which are discussed with recommendations for future research.

Conclusions

This review highlights growing qualitative research in this field and suggests ways to build on this.

Accessible Summary:

- People with intellectual disabilities associate dementia with loss and transition.
- It is important to be able to have choice, a sense of achievement and relationships. Support from other people can help with this.
- People with intellectual disabilities and dementia can participate in research.

- Changes to the way research is done can help this, for example by using visual materials.

Background

Recent estimates suggest that in the UK there are approximately 1.6 million people with intellectual disability, 730,000 of which are above state pension age (Kirk-Wade, 2022). The number of older adults with intellectual disability is increasing as improvements in health and social care increase life expectancy (Sinai et al., 2012). With this comes increasing age-related disorders such as dementia, which some research suggests is almost five times more prevalent in people with intellectual disability than in the general population (Strydom et al., 2013). Research has found that dementia may develop at an earlier age in people with intellectual disability (Takenoshita et al., 2020) and that people with Down syndrome have an elevated risk of developing dementia of up to 90% (Mccarron et al., 2014). With the increasing prevalence has come increasing research, however it remains an under-researched field with more studies needed (Kirwan et al., 2022; Sheehan et al., 2014).

Twenty years ago it was acknowledged that proxy reports could not fully evidence an understanding of dementia, and that there was a need to explore the first-hand experiences (Wilkinson, 2002). Subsequently research evidencing the views and opinions of people with dementia has increased (Patterson et al., 2018; Von Kutzleben et al., 2012; Wilkinson, 2002). This has been replicated in the field of intellectual disability with an increasing focus on the involvement of people with intellectual disability in decisions and research; with a subsequent increasing body of research exploring the perspectives of people with intellectual disability (Beail & Williams, 2014). For people with co-occurring intellectual disability and dementia, the International Summit on Intellectual Disability and Dementia in 2016 highlighted that these advances in self-advocacy and consideration of perspectives and wishes is lagging behind (Watchman & Janicki, 2019). One of the key areas of recommendation was to ensure perspectives of people with intellectual disability are heard more readily on the topic of dementia.

There can, however, be anticipated or real barriers to people with intellectual disability with or without dementia participating in research more readily. These include ethical difficulties such as consent and capacity, communication difficulties, level of cognition as well as researcher views, skills and experience (Crook et al., 2016; Shepherd et al., 2022; Stalker, 1998). Trials involving adults lacking capacity to consent in research trials are perceived to be and actually are more complex due to the complexity of the legal frameworks, the role of gatekeepers, the amount of resource required and a lack of access to training and expertise (Shepherd et al., 2022). However it has been noted that it is often a lack of opportunity and accessible methodology that limits the participation of people with cognitive disabilities in research (Sheth, 2019a) as has been found in the dementia research that appropriate adjustments can overcome perceived barriers, for example through alternative methodology and wider knowledge (Wilkinson, 2002).

Given the high rates of dementia among people with intellectual disability it is important to further understand this better through hearing first-hand experiences of people with intellectual disability (Watchman & Janicki, 2019; Wilkinson, 2002). It is important to identify what research has been undertaken and bring it together in order to highlight the views and experiences of this people group and improve understanding. It is also important to consider the methods that have been used to include people with intellectual disabilities with dementia in research in order reduce any potential barriers to research and help grow to the literature in this field (Sheth, 2019a; Wilkinson, 2002).

At the time of writing, the author was aware of no existing reviews exploring views and experiences of dementia from the perspective of people with intellectual disabilities. During the process of this review a similar one investigating experiences of people with intellectual disabilities and dementia, was published (Jacobs et al., 2023). The Jacobs review included eight studies exploring the perspectives of individuals with intellectual disabilities and dementia and their carers. It highlighted experiences of changes in functioning and in social contact as well as a lack of knowledge of dementia diagnosis. The current review aimed to take a slightly different approach, to explore the views and experiences of dementia from the people with intellectual disabilities with and without dementia as well as to review the methodologies used.

Objectives

This systematic review aimed to synthesise the qualitative literature seeking the views and experiences of people with intellectual disabilities in regards to dementia. The primary question that this review sought to answer was:

- What are the views and experiences of dementia from the perspective of people with intellectual disabilities (both with and without co-occurring dementia)?

The secondary research question was:

- What methods are employed to overcome any barriers to participation of people with intellectual disabilities and dementia in qualitative research?

Method

The enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) reporting guide was followed for this review (Tong et al., 2012).

Search Strategy and Eligibility Criteria

Pre-planned searches in three electronic databases were undertaken to identify studies; PsycINFO, Medline, Web of Science. The search strategy included a combination of four concepts; intellectual disability, dementia, qualitative research and views/experiences along with keywords. The search terms are outlined in table 1 and search strategies in Appendix A. As the amount of literature was expected to be small, filters were not applied so as to capture all the possible relevant articles. Reports in other languages were considered if a translation could be obtained. Reference lists and citing articles of included studies were reviewed to identify any further studies.

Identified reports were downloaded from the databases and entered into reference management software EndNote (version X9). De-duplication was done both automatically through EndNote as well as manually by the author.

The SPIDER tool (Cooke et al., 2012) was used to structure the search inclusion and exclusion criteria (see table 2). The author screened titles and abstracts and following this, attempts were made to obtain the full-text of the remaining reports which were reviewed for eligibility. An independent reviewer applied the eligibility criteria to 10% of the titles and abstracts and 50% of the included papers, and the level of agreement was compared in order to review the effectiveness of the eligibility criteria.

Table 1:

Key Concepts and Search Terms

Key concepts	Search terms
Intellectual disability	“Intellectual Disabilit*” or “Learning Disabilit*” or “Down*Syndrome” or “Learning Difficult*
Dementia	Dementia or Alzheimer* or “Major Cognitive Disorder” or Memory
Qualitative Research	Qualitative* or interview* or focus group or “participatory action research” or photovoice or “talking mat*” or “easy*read” or “case study”
Views/Experiences	Opinion* or View* or Perspective* or Attitude* or Experience* or Voice* or Perception* or Participation or Involve* or Engage* or Input or Contribut* or Co*production

Table 2:

SPIDER Table of Study Inclusion and Exclusion Criteria

Area	Inclusion criteria	Exclusion criteria
Sample	- People with intellectual disability with or without dementia	- People without intellectual disability
Phenomenon of interest	- Studies exploring experiences and views of dementia from the perspective of people with intellectual disability - Studies exploring views and experiences of people with intellectual disabilities and dementia on any topic	- Studies only examining the perspectives of staff or caregivers
Design	- Qualitative or mixed-methods studies reporting primary qualitative data (e.g. through participant observation, focus groups or interviews)	- Studies only reporting quantitative data
Evaluation	- Qualitative analysis of views and experiences of people with intellectual disabilities	- Only quantitative methods
Research type	- Peer-reviewed journal articles - Dissertations and theses	- Systematic reviews - Protocols - Editorials - Opinion pieces

Critical Appraisal of Included Studies

The author used the Critical Appraisal Skills Programme (CASP; 2018) Qualitative Studies Checklist to evaluate the included studies and identify the strengths and weaknesses of the studies in a systematic way. The independent reviewer rated half the included studies using CASP and scores were compared to measure agreement in applying the checklist.

The quality ratings of the studies were used in the synthesis approach with studies with the highest CASP scores acting as 'index studies' from which the concepts were first drawn for the synthesis. Studies attributed with low quality scores were not excluded as although they may not have included enough detail to identify if a quality criteria was met, studies might still have valuable insights, and lack of reporting does not necessarily equate to poor research (Atkins et al., 2008).

Data Extraction

The author entered data from the included studies onto a data extraction sheet to summarise the characteristics of the studies in a consistent manner. It was also used to collect and summarise key data about methodology and adaptations to address the second research question on methodology. Information on study aims, participant characteristics, study setting, data collection, qualitative methodology, adaptations and analysis methods were included. The extraction process and areas of uncertainty regarding study characteristics were discussed with the independent reviewer.

Data Analysis

Thematic synthesis (Thomas & Harden, 2008) was used to synthesise the findings of the identified papers to address the first research question. This is a flexible method of qualitative evidence synthesis that can help explore peoples' perspectives which aligned with the first research question of this review.

The first stage of thematic synthesis involves coding the text, so the text of the identified studies was imported into NVivo; software for qualitative data analysis from QSR

International and line by line coding was carried out to search for concepts. Coding was undertaken for all text included in the findings section of the papers, in line with previous studies (McMahon et al., 2022; Thomas & Harden, 2008) which therefore included first and second order constructs. Although the order of coding the papers is not prescriptive when using thematic synthesis, the studies with the highest CASP score were coded first in this review which is an approach often used in other qualitative reviews as papers read first by the reviewer can have a stronger influence (Sattar et al., 2021). Separate codes were created to capture whether the code related to a person with or without dementia in order to track whether codes applied to one group or other.

The second stage of thematic synthesis involves developing descriptive themes (Thomas & Harden, 2008), therefore the codes that were identified were organised into a hierarchical structure of descriptive themes by examining the similarities and differences between the codes identified in NVivo. This was done both using NVivo and manually by drawing out mind maps.

The third stage of thematic synthesis involves developing analytical themes (Thomas & Harden, 2008). Some of this process happened in the second stage, however some descriptive themes needed a further analytical stage to move to analytical themes that addressed the research question (McMahon et al., 2022). This inductive and deductive process was done manually by writing out ideas about the views and experiences captured by the themes and in relation to the literature.

To address the second research question, extracted data on methodology and any adaptations to the methods made were reviewed by the author and reported on descriptively.

Researcher Reflexivity

The researcher is a white female in her 30's with a small amount experience of working with people with intellectual disabilities and substantial experience working with older adults with and without dementia, their carers and staff teams. The researcher tried to minimise preconceptions by bracketing beliefs from the start and throughout of the process of the review using a reflexive journal (Ahern, 1999; Tufford & Newman, 2012).

Results

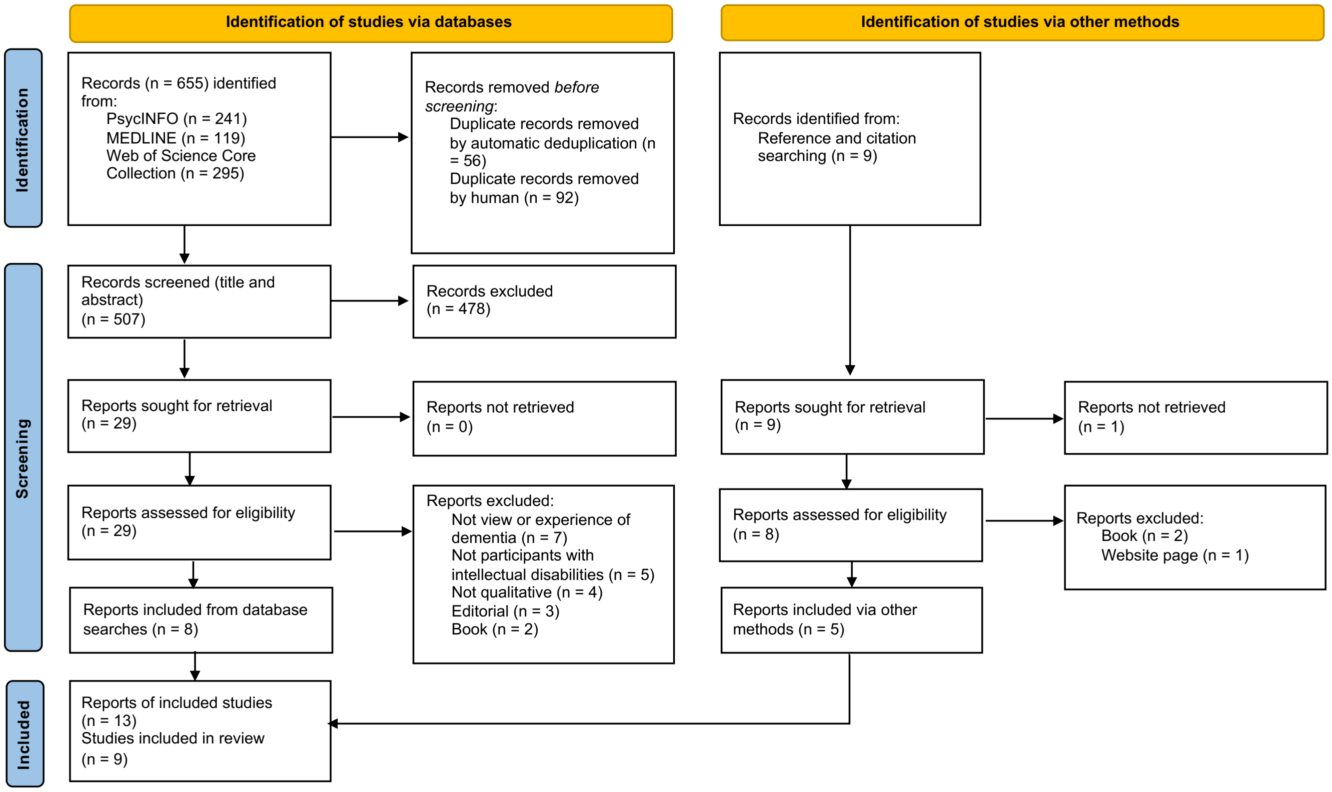
Results of the Search

The study selection process is outlined in the PRISMA Flow Diagram (Figure 1). Database searches were carried out on the 14th September 2022 and found a total of 655 records. After duplicates were removed a total of 507 titles and abstracts were reviewed against the eligibility criteria. Following this, 29 records were selected for full-text review and eight met the full criteria to be included in the review. A further five records were identified through reference and citation searches giving a total of 13 records.

On reviewing the records that met the criteria, it was identified that three of the studies were presented in more than one report, for example a doctoral dissertation and a peer reviewed publication or two peer reviewed publications reporting on different aspects of the same study. Where that was the case the multiple reports were treated as one study. One study (Sheth et al., 2021) carried out a secondary analysis of the same data presented in another study (Sheth, 2019a). The participants were the same however the research question and analysis method differed. These reports were therefore treated as separate studies, though care was taken not to duplicate reporting of participants. This resulted in a total of nine studies outlined in table 3. There was agreement between the researcher and the independent reviewer on the included studies.

Figure 1

PRISMA Flow Diagram of the Searches



Description of the Studies

Across the studies there were a total of 37 participants for which qualitative data was reported (22 with dementia and 15 without) with an age range of 37-61 and a mix of male and female participants although some studies did not report this data. Two studies reported ethnicity data with all participants reported as “White” or “White European”, the other six studies did not report ethnicity data. All studies were from the UK or North America.

A variety of qualitative methodologies were employed within and between the studies. Interviews were used in seven studies, this included semi-structured interviews (Forbat & Wilkinson, 2008; Lloyd et al., 2007; Lynggaard & Alexander, 2004; Temple, 2002), adhoc unstructured interviews alongside observations (Sheth, 2019a; Sheth et al., 2021), interviews using nominal group technique (Sheth, 2019b, 2019a) and semi-structured interviews as part of photovoice methodology (Watchman et al., 2020). Photovoice methodology is participatory action research which uses photographs as a means of data collection which are then discussed (Wang & Burris, 1997; Wang & Redwood-Jones, 2001). Across the studies, interviews lasted from 5-90 minutes, they were facilitated one-to-one and in groups, both with and without carers present and were audio recorded.

Ethnographic and observation based methods were utilised in six studies (Forbat & Wilkinson, 2008; Manji, 2008; Sheth, 2019a; Sheth et al., 2021; Watchman, 2013; Watchman et al., 2020). Observation period was not always reported but of studies that did report this, the period of observation lasted up to three years (Watchman, 2013) and visits lasted between 15 minutes and 8 hours across studies. Studies reported audio recording observations as well as taking field notes.

Quality Assessment of the Studies

The results of the CASP checklist are displayed in table 3. All studies stated their aims, justified the research methods and design, collected data in a way that addressed the research question and presented their findings. Five studies gave clear descriptions of the recruitment process with the others not reporting on this at all or in a limited way. Four studies described the researcher’s role and/or potential preconceptions. All but one study reported having ethical approval and referenced consent procedures, one study did not report this information.

Table 3

Characteristics of Included Studies

Author (year)	Study aims	Number of participants Setting	Age range Sex Ethnicity	Qualitative methodology and analysis	Key findings
Forbat & Wilkinson (2008)	To explore how people with intellectual disability understand dementia and implications for housing	With dementia = 8 (only data from 2 used) Without dementia = 8 Residential home in the UK	Age, sex and ethnicity not reported	Interviews and ethnographic observations however observation data was not reported. Thematic analysis	- People with intellectual disabilities can know a lot about dementia including signs and symptoms and impact of that. - People with intellectual disabilities were aware of potential environmental changes and consequences but there was little consultation or communication about this. - When some residents in a home have dementia other residents can feel they have less staff time or privileges. - People with intellectual disabilities and dementia had been told their diagnosis but did not seem to have an understanding of it. However, they did have an awareness of the impact of their symptoms on others and general aging.
Lloyd et al. (2007)	To explore the perspectives and subjective experiences of people with Down Syndrome and Dementia	With dementia = 6 Without dementia = 0 Residential home for intellectual disabilities in the UK	Age = 49-59 M = 4 F = 2 White European = 6	1:1 Semi structured Interviews Interpretative phenomenological analysis	- Adjustment to having dementia for someone with intellectual disability was comparable to the general population, however with context specific levels. - Having roles and jobs is an important sign of independence. People with intellectual disabilities still see themselves as independent but opportunities for this diminish in dementia. - Relationships are important, people with intellectual disability and dementia have a desire to maintain relationships, increasingly rely on others, especially staff and sometimes encounter relational difficulty. - Some people with intellectual disabilities and dementia recognise cognitive decline, more identify physical decline. Some experienced a sense of loss and distress and there was some implicit evidence of coping strategies.
Lynggaard and Alexander (2004)	To create opportunities for understanding more about dementia and the effects of living with others who develop dementia for people with intellectual disability.	With dementia = 0 Without dementia = 4 Residential home in the UK	Age = 37-54 M = 2 F = 2 Ethnicity not reported	Semi-structured interviews Data analysis method not reported	- People with intellectual disabilities noticed changes in others who had developed dementia but did not attribute this to dementia or memory related changes. They thought the changes in behaviour were within the person with dementia's control. - After an intervention focused on increasing understanding of dementia in others, participants better understood that changes in behaviour were not within the person's control and increased helping behaviour and strategies for coping with changed behaviours.

Author (year)	Study aims	Number of participants Setting	Age range Sex Ethnicity	Qualitative methodology and analysis	Key findings
Manji (2008) This is a doctoral dissertation, the findings of which are also reported in Manji & Dunn (2010)	To explore how dementia changes needs and support for people with intellectual disability and how people with intellectual disability and dementia experience living in a home specializing in dementia support.	With dementia = 4 Without dementia = 0 1 lived in supported independent living; 2 in group homes; 1 in family home in Canada	Age = 49-59 M = 1 F = 3 Ethnicity not reported	Observation Grounded theory	- People with intellectual disabilities and dementia experience losses in ability, home and community. - They maintain selfhood with good health support decision-making, self-agency and autonomy. - Good health support includes emotional support, particularly around grief. - Self in the community is important through maintaining connections with wider community activities and social lives. - Staff empowered people with intellectual disabilities and dementia to maintain selfhood, freedom and choice and involvement in community, through empathy, compassion, commitment and affection - Lack of resources, including staffing and funding restricted the quality of support that could be given.
Sheth (2019a) This is a doctoral dissertation, the findings of which are also reported in Sheth (2019b)	To explore the perspectives on environmental influences on participation and consider what methodological and accessibility considerations might support participation in research by people with intellectual disabilities and dementia	With dementia = 4 Without dementia = 0 Community group homes for 6 or less in the USA	Age = 45-61 M = 0 F = 4 White = 4	Nominal group technique sessions analysed with thematic analysis. Ethnographic observations over 6 months with unstructured interviews analysed using a grounded theory approach and an ecological systems framework	- Activity access is important including consistency, choice and agency - Caregivers can both facilitate and limit choice and participation. Quality of relationship with staff and staff availability affects whether people ask for support. - Positive social interactions facilitates participation, negative interactions are a barrier. - Roles and responsibilities are important in day-to-day life which includes roles and responsibilities in relation to domestic tasks as well as relationships. - Privacy and ability to be physically separate from others is important which can be difficult in shared accommodation. - Good health and wellness facilitate participation, stress of self and others is a barrier.
Sheth et al. (2021) This is a secondary analysis of part of the data in Sheth (2019a). Participants and methodology are the same.	To explore the experiences of transition from the perspectives of people with intellectual disabilities and dementia.	With dementia = 4 Without dementia = 0 Community group homes for 6 or less in the USA	Age = 46-61 M = 0 F = 4 White = 4	Ethnographic observations over 6 months with unstructured interviews Thematic analysis used to analyse data	- People experience a lot of home moves which comes with positives such as new friends and space, as well as sadness, grief, and not having choice. - Seeing photos and people or places from the past help people engage with transition. - Peer networks are a support to transition but are also sometimes disrupted by changes in housing. - Anticipation and threat of future transitions affects daily life. There can be a fear that independence could be removed if not adhering to schedules, rules, regulations or expressing negative emotions

Author (year)	Study aims	Number of participants Setting	Age range Sex Ethnicity	Qualitative methodology and analysis	Key findings
Temple (2002) This is a doctoral dissertation	To compare socio-affective and behaviour changes accompanying Alzheimer's disease in people with Down syndrome and the general population.	With dementia = 2 interviewed Without dementia = 0 Canada, setting unclear.	Age = 40-60 M = 1 F = 1 Ethnicity not reported	Semi structured interviews lasting 5-15 minutes Data analysis method not reported	- People with dementia and intellectual disabilities can recognise changes in memory - This is not always associated with sadness or concern but can be associated with ongoing positivity.
Watchman (2013) This is a doctoral dissertation. The findings are also reported in Watchman (2016)	To explore the methodological and ethical issues that arose during a longitudinal study of the lived experiences of dementia in three adults with Down syndrome.	With dementia = 3 Without dementia = 0 Intellectual disability group home (n = 1) Single tenancy with outreach support (n = 1) Generic care home for older people (n = 1) UK	Age = 47-60 M = 1 F = 2 Ethnicity not reported	Longitudinal ethnography Thematic analysis and cross case comparison	- Sense of self is maintained for people with intellectual disabilities and dementia and is not dependent on verbal ability. This is displayed in three aspects: - Firstly, through ability to reflect own views, - Secondly, through insight into physical mental or emotional attributes and characteristics, - Thirdly, through social interactions - There is a lack of shared diagnosis, a lack of answers led to more fears. - People experience exclusion and isolation, and losses of relationships, participation in social activities and decision making.
Watchman et al. (2020) This paper reports on the photovoice methodology part of the wider project reported in Watchman et al. (2021). The reports have the same participants and findings.	To explore the benefits and challenges of co-researchers with intellectual disability engaging with photovoice and whether this contributes new knowledge about dementia in people with intellectual disability.	Termed 'co-researchers' in this paper: With dementia = 1 Without dementia = 3 Setting of co-researchers not reported UK	Age, sex and ethnicity of co-researchers not reported	Photovoice methodology Thematic analysis	- Despite knowing peers who had developed dementia, participants had limited knowledge of dementia prior to the study. - Dementia is associated with fear and uncertainty and sense of loss and unknown, compounded by dementia not being explained. - Friendship and support from peers, family and especially staff is seen as important - Transitions in accommodation can be a barrier in maintenance of support and friendship. - People have question about the future about want to be involved in future care decisions, accessible information is important for this.

Table 4

CASP Quality Assessment Summary

Author (year)	Aims stated and justified	Qualitative methodology appropriate	Research design	Recruitment strategy	Data collection	Researcher role	Ethics	Data analysis	Statement of findings	Value of research	CASP score
Forbat & Wilkinson (2008)	Yes	Yes	Yes	No - Not reported	Yes	No - Not reported	Yes	No - Not enough data to sufficiently analyse	Yes	Yes	7
Lloyd et al. (2007)	Yes	Yes	Yes	No - Not enough detail	Yes	No - Not reported	Yes	Yes	Yes	Yes	8
Lynggaard and Alexander (2004)	Yes	Yes	Yes	Yes	Yes	No - Not reported	No - Not reported	No - Not reported	Yes	Yes	7
Manji (2008) Manji & Dunn (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Sheth (2019a) Sheth (2019b)	Yes	Yes	Yes	Yes	Yes	No - Not reported	Yes	Yes	Yes	Yes	9
Sheth et al. (2021)	Yes	Yes	Yes	Yes	Yes	No - Not reported	Yes	Yes	Yes	Yes	9
Temple (2002)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Watchman (2013) Watchman (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Watchman et al. (2020) Watchman et al. (2021).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10

Research Question One Findings: Thematic Synthesis Findings

Analysis of the study findings resulted in three main interconnected analytical themes with six further subthemes: dementia is associated with transition and loss (loss of ability, transitions in accommodation and loss of relationships and connection); the importance of maintaining a sense of self (through maintaining choice, maintaining competence, maintaining relational connection) and support counteracts loss. It is noted whether quotes are directly from participants, and/or from researcher observations or commentary.

Dementia is Associated With Transition and Loss

The experiences of loss and transition were present in most studies, identified by and in the accounts of participants with and without dementia (Forbat & Wilkinson, 2008; Lloyd et al., 2007; Lynggaard & Alexander, 2004; Manji, 2008; Sheth et al., 2021; Temple, 2002; Watchman, 2013, 2016; Watchman et al., 2020). The subthemes of loss of ability, transitions in accommodation and loss of relationships and connection highlight three key areas of this.

Loss of Ability

Thirteen participants with dementia had not been told about their diagnosis of dementia (Lloyd et al., 2006; Sheth, 2019a; Sheth et al., 2021; Watchman, 2016), and participants who had been told did not remember this. Some did not recognise any difficulties with their cognitive abilities. However a number of participants were aware of changes in their cognition.

> *Researcher: "Neither of the residents seemed to know the word 'dementia' although staff reported that this has been shared with Belinda"* (Forbat & Wilkinson, 2008)

> *Participant: "They tell me and I keep forget, yeah. Yeah, errm they told me Julie, I forgot the name, Julie. I can't think, yeah."* (Lloyd et al., 2007)

Participants with dementia seemed more aware of their physical decline compared to their cognitive decline. Participants were also aware of the impact of changes on their life and no longer being able to do things they previously had been able to do.

> *Participant: "Hard to put away clothes. Hard on my legs to go up and down stairs."* (Temple, 2002)

> *Participant: "I retired from [work at a café]…it was too much for me. It's hard to let go. I've had to stop so much. I've had to retire from everything."* (Sheth et al., 2021)

Distress related to these losses in ability was present in accounts by those with and without dementia. Distress and frustration related to cognitive changes was present as well as fear about what these losses would mean in the future.

> *Researcher: "Andrew became agitated and frustrated at his own lack of memory, which increased over time. By year two there was a noticeable deterioration in his ability to remember individual words such as 'day'"* (Watchman, 2013)

> *Participant: "Yeah (pause), I don't want to pass away. I don't want to get old. I don't want to go to heaven. I can't, I can't lose it. The way things are."* (Lloyd et al., 2007)

Participants who did not have dementia noticed specific changes in the behaviour of others with dementia, though did not necessarily attribute this to dementia.

> *Researcher: "Seven main issues were apparent, and occurred frequently in the talk of panel members, and indicate their understandings of dementia. These were: 1. Confusion. 2. Forgetfulness. 3. Wandering. 4. Health and safety…"* (Forbat & Wilkinson, 2008)

> *Researcher and participant: "[Participants] had little or no understanding that the changes in their housemates' behaviour were the result of [dementia] … one person said that the housemates `should pull themselves together', and another said that `they are lazy, like a baby'."* (Lynggaard & Alexander, 2004)

Dementia had not been explained to participants who did not have dementia which led to fears. However they were better able to understand dementia and attribute behaviour changes to this once it was explained and discussed with them.

> *Researcher: "Although a number of their peers had developed dementia, the progression of dementia was not something that had been explained, nor was it evident in their observations during the study. This left co-researchers with fears about progression of dementia from both a health and well-being perspective".* (Watchman et al., 2020)

> *Researcher: "When we met again with participants after 6 months, it was clearer from their comments that they all attributed many of the changes in their housemates to the effects of an illness over which the individual with dementia might not have control".* (Lynggaard & Alexander, 2004)

Transitions in Accommodation

For participants with and without dementia, changes in accommodation as a result of dementia or related changes was something that was mentioned frequently. These transitions were often due to changes in mobility or in the case of one participant was due to their carer being hospitalised. These transitions in accommodation were generally decided on behalf of the person with dementia rather than being their choice.

> *Researcher: “She subsequently moved to her current setting when her mobility deteriorated and prevented her from climbing stairs.”* (Watchman, 2013)

> *Researcher: “Rose had previously lived with a sibling until her sister was hospitalized and was subsequently considered too frail to care for her. With no forward planning for such a crisis situation, Rose was moved to the nearest care home with an available bed, which was where she had remained for the previous 4 months.”* (Watchman, 2016)

Some participants spoke positively about this transition, whereas others were not happy about the transition, or expressed fears and concerns about transitions in the future and the implications of this.

> *Researcher and participant: “Jennifer shared that she was “kind of sad to move out, but I got over it though. I was happy at [former home]. But, I like it here being at [current home]”.”* (Sheth et al., 2021)

> *Participant: “…people might be a bit frightened that they might have to go into a long stay hospital, or an institution, if things get really bad … I want to stay where I am as long as I can. I don’t want a new team. But I know in the end it’s sometimes … That’s the thing that bothers me, I don’t know how long … different circumstances might mean having to move … It’s like a question mark.”* (Watchman et al., 2020)

Loss of Relationships and Connection

Participants also spoke about loss of relationships with peers, family and staff due to dementia. Those with and without dementia experienced loss through the death of peers with dementia.

> *Researcher: "'Shortly after eating, Donna began crying and pointing to the picture of [name] by the front door.' In this situation, it was obvious that Donna was expressing grief for a dear friend and housemate with dementia who had passed on."* (Manji, 2008)

> *Participant: "there were four people I knew when I was at the centre, and they all got dementia. And they've all gone now, just disappeared. I don't know if it was that that killed them, I don't know. But four people.*" (Watchman et al., 2020)

Loss of relationships with peers and staff teams also came from the transitions in accommodation that accompanied their own or others' dementia. In a number of accounts, participants were facilitated to maintain these relationships, and in others, participants coped with this by forming new friendships.

> *Researcher and participant: "Karen did have opportunities to see some peers and staff from her previous residence at leisure activities through the organisation. She often responded with affection and a positive affect when seeing them. For example, when seeing an old friend at a crafting group. Karen reached out to hold their hand and commented, "It's not the same without you""* (Sheth et al., 2021)

> *Researcher and participant: "Charlie simultaneously acknowledged the coping method of replacement with another relationship: Charlie: 'Sally is my best friend now. I miss Rose.'"* (Lloyd et al., 2007)

Relational disconnection was also present in accounts, which seemed to come about when participants were not aware or did not acknowledge their difficulties when it was evident to others.

> *Researcher: “Generally, participants commented that it had become much harder to have conversations with the two people with dementia and that there were many more arguments in the house.”* (Lynggaard & Alexander, 2004)

> *Participant: “Alice: I’m alright, it’s lovely (referring to her role working voluntarily in a coffee shop). ‘Cept one person’s been picking on me, saying I’m doing it wrong. I don’t know why ‘cause I’m not.”* (Lloyd et al., 2007)

The Importance of Maintaining a Sense of Self

Many accounts referenced the importance of maintaining a sense of self both explicitly and implicitly (Lloyd et al., 2007; Manji, 2008; Sheth, 2019a, 2019b; Sheth et al., 2021; Temple, 2002; Watchman, 2013; Watchman et al., 2020). The interconnected subthemes of maintaining choice, maintaining competence and maintaining relationships seemed to be key in the maintenance of a sense of self.

Maintaining Choice

Ability to make choices was evident explicitly and implicitly in many different domains including choosing food, clothes or activities to engage in, whether to engage or have time alone, what to buy and how to decorate a room.

> *Researcher: “’Staff is trying to find out what Jim would like to eat today. She signs, 'Chinese Rice?' Jim gets excited and nods his head smiling.’ Similarly, I observed individuals deciding what to wear, which bathroom to use, when to go to bed, and what to do with their time.*” (Manji, 2008)

> *Researcher: “the women frequently emphasized a subtheme of choice and agency. This occurred not just in the activity content, but valuing a mixture of sharing activities with others and doing activities alone, enjoying both familiar and novel activities, and seeking opportunities for independence and assistance”* (Sheth, 2019b)

The importance of having choice in decisions about the future was also evident in accounts from those with and without dementia.

> *Researcher: "The inside pages [of the funeral order of service] detailed the songs, hymns and readings that were to follow, with a statement that all were chosen by Lucy."* (Watchman, 2013)

> *Participant: "I think one of the things that's important for them to know is to think about what is going to happen in a few months or years and what they need to do to the house—who can help with that?"* (Watchman et al., 2020)

Participants communicated choices in a variety of ways; verbally, signing, or through non-verbal behaviour, for example choosing to not engage in an activity when needing to be present. Participants without dementia also highlighted how accessible information can support choice and make plans for the future.

> *Researcher: "Karen initially did not engage in this structured programming, notably walking off from the main activity. When told several times that she needed to come join the group, she walked over at sat with the other participants, but did not engage."* (Sheth et al., 2021)

> *Researcher: "Accessible information was perceived as being part of this to help support people with intellectual disabilities both to understand dementia and plan for the future."* (Watchman et al., 2020)

Maintaining Relational Connection

The importance of relationships and desire for connection with others was identified by those with and without dementia.

Researcher and participant: “*PR says […] she ‘likes to be with people’”* (Temple, 2002)

Participant and researcher: [Photograph of a group of approximately 4 people standing in a circle, holding hands] “It is important to meet up with friends and catch up.” (Watchman et al., 2020)

Participants with dementia valued their families and desired to spend time with them even when that became difficult.

Researcher and participant: “Jennifer also frequently talked about her plans to move out of her [supported accommodation] and return to living with her parents. When probed, she disclosed that while she would like to live with her parents, ‘That's just not an option’.” (Sheth et al., 2021)

Researcher: “He looked for explanations of what it meant to have a stroke, why his Dad couldn’t move on one side of his body, why he was unable to speak and why Andrew could no longer visit him every weekend.” (Watchman, 2013)

The importance of peer friendships was explicit and implicit in the accounts of the participants with intellectual disabilities and dementia. Peer relationships were outlets for fun as well as support and were not one sided but had a reciprocal nature.

> *Researcher and participant: “When Cynthia became visibly upset talking about the death of her mother years ago, Jennifer replied, ‘You can lay on me, if it makes you feel better’. Cynthia and Jennifer hugged and provided condolences for their housemate who shared funeral memorial cards of her parents who died several years ago.”* (Sheth et al., 2021)

> *Researcher: “Jim comes out of his room. He is making playful and friendly gestures to Jenny and Donna sitting in the living room. He goes up to another housemate who has just come home. He strokes, hugs, kisses, and playfights with her on the sofa. Then they chase each other into the kitchen. They are laughing and appearing to be having a lot of fun.”* (Manji, 2008)

> *Participant: “I help out when people need help […] [friend] help me out and I help her out.”* (Sheth, 2019b)

Participants found ways to maintain connection in a way that was not affected by dementia. This included having imagined interactions with family or friends and staff sometimes taking on the role of friends as well as carers.

> *Researcher: “In Mark’s case, he had also developed an elaborate ‘fantasy family’ who he described spending long periods of time with.”* (Lloyd et al., 2007)

> *Participant: “Charlie: Louise and Jane (residential home carers), they’re my friends. Erm (pause) There’s no one else. What do you mean?”* (Lloyd et al., 2007)

Maintaining Competence

Participants’ ability and desire to maintain areas of competence was present implicitly and explicitly in accounts, despite the losses in ability associated with dementia. This was evident in a variety of domains including competence in relational abilities, competence in areas of interest, or ability to carry out tasks or chores.

> *Participant: "Interviewer: Can you remember things ok? Charlie: I can yes. But it's a bit bad. But I know this (spells out own name with fingers)."* (Lloyd et al., 2007)

> *Researcher: "He maintained a good long-term memory for facts and figures if they related to topics of interest to him, such as football. He asked me how old I was when I got married, how old I was at that time and instantly worked out the number of years that I had been married."* (Watchman, 2013)

Roles and responsibilities seemed to be a key part of participants' maintaining a sense of competence. This included valuing being able to carry out practical tasks, as well as having relational roles and responsibilities:

> *Participant: "Mary: Oh I like that, it's lovely. I set the table up, clean the table, mop the floor, sweeping the floor. (pause) Oh I like it, it's lovely."* (Lloyd et al., 2007)

> *Researcher: "When talking about their work or leisure activities, they discussed strong identification in roles such as worker or artist, as well as their responsibilities within their family roles, such as aunt, great-aunt or godmother, as well as being a friend or romantic partner.*" (Sheth, 2019b)

Where dementia was linked with a more significant loss of ability it seemed that participants fulfilled their desire to have a sense of competence by taking on simple tasks as their role or job to complete. Even in the latter stages of dementia, competence to communicate and maintain specific interests was present.

> *Researcher and participant: “JF spent a good deal of time sorting Christmas cards back and forth into piles. He makes reference to this activity when he says ‘Well, I got a lot of cards to do today’”* (Temple, 2002)

> *Participant: “Interviewer: What are your jobs? Billy: Erm (pause) erm (pause) I like turning the lights on and off.”* (Lloyd et al., 2007)

> *Researcher: “As time passed, and Hannah’s dementia progressed, I was unsure if she would remember or maintain her interest in bags although this proved unfounded. Researcher: Hannah would you like the bag? [Field notes: Hannah inaudible - high pitched but not distressed, calm and smiles then screeches loudly, takes bag, strokes it]. Researcher: [Calming voice] That’s okay.”* (Watchman, 2013)

There seemed to be attempts to retain the appearance of competence even in the face of loss of ability, though it was unclear whether this was due to a lack of insight or a conscious strategy to maintain a sense of self.

> *Researcher and participant: “Instead of talking about difficulty, she chose to speak about what she enjoys. She states that ‘Going to program is easy’ and that she likes ‘crafts and bingo’”* (Temple, 2002)

> *Researcher: “Andrew was quick to say that he was coping, but observations suggested otherwise; for example, evidence of his varied and nutritious cooking becoming the same frozen ready-meal every day of the week”* (Watchman, 2016)

Support Counteracts Loss

The accounts of participants highlighted the important role of others in counteracting the losses associated with dementia and to support individuals in maintaining a sense of self

(Lloyd et al., 2007; Lynggaard & Alexander, 2004; Manji, 2008; Sheth, 2019a; Watchman, 2013, 2016; Watchman et al., 2020).

Choice was facilitated when peers and carers empathised and understood wishes and desires. Conversely, when others had a lack of knowledge of dementia or a person’s abilities and wishes, this was a barrier to choice for people with dementia. For example, when a carer did not know that residents might need physical support to pick up food this impacted the fundamental ability to choose whether or not to eat.

> *Researcher: “Jenny goes in her bedroom, and staff member follows to see what she wants to do. When staff comes back in the living room, she tells me that Jenny stood in her room. When staff asked her if she wanted to go to bed, she said 'Nein.' Then staff asked her if she wanted to go to the living room. She said, 'Nein.' Then staff asked her if she needed a hug. She said, 'Ha!' Staff gave her a hug, and Jenny crawled into bed. Staff said Jenny had decided to go to bed early today.”* (Manji, 2008)

> *Researcher: “The care assistant continued to give out slices of melon, no one is given any help to eat and only one of the thirteen residents in the room picks up the melon and eats with their hands. Hannah continues to make pincer movements and makes the action of eating from her hand but does not pick any food up.”*
> (Watchman, 2013)

Support from others helped participants maintain competence and independence, with staff taking time to include and support people with dementia to carry out tasks rather than doing it for them. This seemed to give participants a sense of achievement.

> *Participant: “I don’t need any other help. Louise (staff caregiver) has to do my bed for me sometimes. But I help as well.”* (Lloyd et al., 2007)

> *Researcher: "She gives him a can opener and Jim tries to open the can. He tries one and finds it difficult. Staff comments to me that Jim is gradually losing this skill. He used to open cans all the time. She gives him another opener and shows him how to use it. With constant reminders on how to turn the knob he succeeds in opening the soup can. He continues in this manner to open the remaining cans. He is excited each time he has completed opening a can."* (Manji, 2008)

Support from others also helped participants maintain relational connection, and lack of awareness of relational needs hindered this.

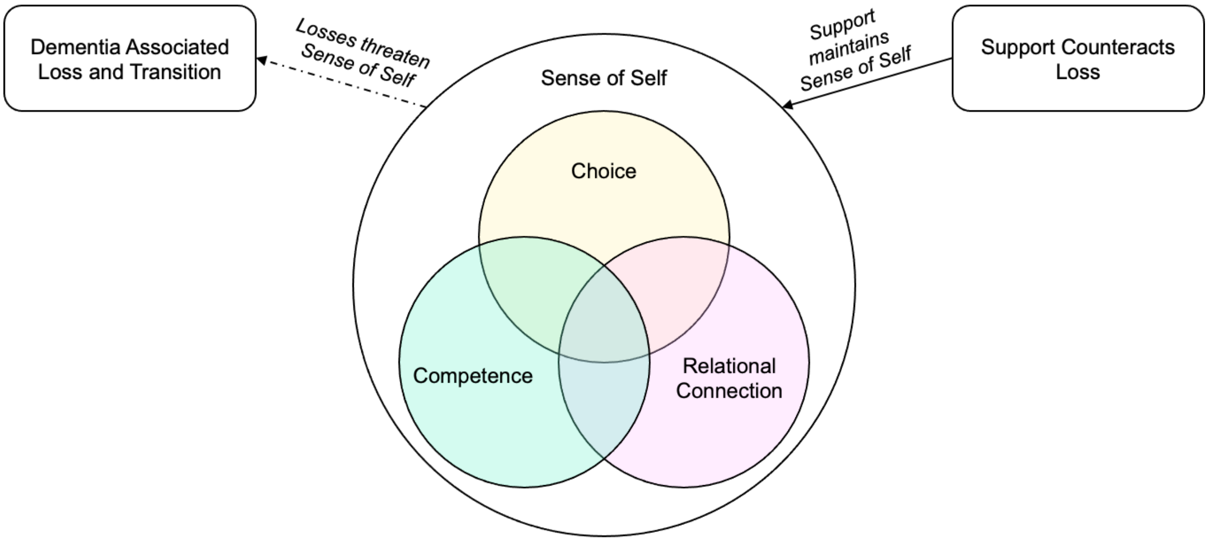
> *Researcher: "staff facilitated participation, interaction, and relating with others, keeping alive the opportunity to employ the growth of self of the consumer who was at risk of being "lost" in the dementia experience."* (Manji, 2008)

> *Researcher: "Rose was not observed to interact with staff or other residents causing staff at one point to ask why Rose was always so pleased to see the researcher, why communication appeared easier between the two than between Rose and staff, and with the question asked if Rose "could talk when she was a young girl." Rose could talk when she moved into the care home but was not engaged in conversation by staff."* (Watchman, 2016)

As the analytical themes were developed it seemed that they were not isolated concepts but connected. The losses and transitions associated with dementia seemed to be threatening the sense of self, and conversely the support people received seemed key in maintaining the sense of self and to counteract the effects of the dementia. The themes of choice, competence and relational connection had some level of overlap, for example, participants demonstrated choice and competence in relationships. The relationships between the themes are depicted in figure 2.

Figure 2

Diagram of How the Analytical Themes Relate to Each Other.



Research Question Two Findings: Methods to Include People With Intellectual Disabilities and Dementia in Qualitative Research

Studies involving participants with intellectual disabilities and dementia included a number of adaptations to make this possible. Three studies highlighted this explicitly; one focusing on overcoming methodological and ethical challenges (Watchman, 2016) one including guidelines for research with this population (Manji, 2008) and one describing the adaptation of Nominal Group Technique for use in this population (Sheth, 2019a).

Addressing Ethical and Consent Challenges

Due to participants not knowing their dementia diagnosis, one study asked carers about awareness of diagnosis in advance (Sheth, 2019a) and studies avoided the language of ‘dementia’ or ‘Alzheimer’s’ in interactions or on patient facing paperwork (Lloyd et al., 2007; Sheth, 2019a; Watchman, 2016).

Studies adapted consent forms and processes for accessibility including using pictures (Manji, 2008; Sheth, 2019a; Watchman, 2016). Consent was seen as an ongoing process in some studies, with assessment of a person's wishes to remain involved at each research activity, including paying attention to consent communicated through body language and non-verbal cues e.g. by leaving the room (Manji, 2008; Watchman, 2016).

Adaptations for Communication Challenges

Studies referenced using simplified written and verbal language and verbally explaining instructions rather than just relying on written instructions. Researchers also helped participants understand by reframing questions and using examples. Large fonts were used for written text with pictograms used alongside words to facilitate understanding (Sheth, 2019a). The use of sign language was used in one study (Manji, 2008) with another mentioning it as a helpful approach to facilitate communication (Lloyd et al., 2007).

Addressing Data Quality and Quantity Challenges

The verbal data gathered from interviews with people with intellectual disabilities and dementia was often limited, for example only two of eight participants in one study gave substantive enough data to report on (Forbat & Wilkinson, 2008). However studies addressed this by using multiple approaches to data collection and cross referencing. For example triangulating from case records and/or interviews with staff or family carers (Forbat & Wilkinson, 2008; Manji, 2008; Sheth, 2019b), though data from participants without intellectual disability was not included in this review. Studies also cross referenced data between interviews and observations (Forbat & Wilkinson, 2008; Sheth, 2019a; Sheth et al., 2021). The use of field notes in observational methods enabled researchers to capture non-verbal data such as body language, facial expression, interaction with people and objects and tactile interactions. This was especially important when verbal communication was limited.

Taking a longitudinal approach enhanced the quality of the data by enabling the researcher to build an understanding over time of the meaning of noises and expressions when participants were unable to communicate with words (Manji, 2008; Watchman, 2013, 2016). It was also beneficial for balancing gathering data with not being overly intrusive (Watchman, 2013, 2016).

Addressing Challenges in the Latter Stages of Dementia

One researcher highlighted the need to allow more time for participants to respond as sometimes they responded with a relevant response a while after the question was asked (Watchman, 2013). The same researcher noted the use of music being beneficial as one participant could sing for longer than she could speak, as well as the use of touch as a means of communication in the late stages of dementia. The use of objects of reference was also used by this researcher to structure the observations; with a bag with photos, voice recorder and ID badge signalling the start of the visit.

Other Methodological Adaptations

Other considerations that researchers made were meeting with participants prior to interviews to discuss the process and to develop rapport (Lloyd et al., 2007; Manji, 2008), with one study reflecting that it would have been helpful to offer a practice session (Sheth, 2019a). Most studies did not include carers in interviews however one study noted that carers helped with prompts to elaborate, with rephrasing or clarifying things for the researcher (Sheth, 2019a).

Alternative Qualitative Methodologies

Alongside regular interview and observation methods discussed, one study used Nominal Group Technique to enable participants to engage in a dynamic process and generate ideas to contribute to the research (Sheth, 2019a). The nature of the group technique meant that those who were not able to generate ideas were able to benefit from others’ ideas. However not all participants were able to engage in this methodology which was at times a distraction and although pictograms were used the methodology still relied heavily on written text.

Discussion

This review provides insight into the views and experiences of dementia from the perspective of people with intellectual disabilities. Findings show a sense of loss and transition related to dementia, which is associated with fear when not explained. A sense of self is upheld through maintaining choice, competence and relational connection, and support from others is a facilitator or barrier to that. This review also demonstrates that it is feasible to involve participants with intellectual disabilities and dementia in qualitative research and highlights a number of adaptations to facilitate this.

Views and Experiences of People with Intellectual Disabilities and Dementia

The findings echo dementia research in the general population which found similar themes around loss, uncertainty, desire for value and meaning to the end through connection, roles and care from others (Bolt et al., 2022; Read et al., 2017) and capacity for choice, competence and connection (Birt et al., 2020; Boyle, 2014; Smebye & Kirkevold, 2013). Although it has been debated, the literature generally suggests that a sense of self or identity persists in dementia with some aspects of self deteriorating as the disease progresses (Caddell & Clare, 2010). The findings build on this discussion by suggesting that people with intellectual disabilities and dementia also experience loss related to dementia as well as express a sense of self to the latter stages of dementia.

Thomas Kitwood’s work, which was fundamental in the move to person centred care in dementia, posited that other people are crucial in the maintenance of a person’s sense of self as it diminishes in dementia (Kitwood, 1997a). This review demonstrates this important role of others, with good support contributing to maintaining a sense of self. It also aligns with the idea that as verbal or conscious communication declines, there is an increasing need for carers to understand unconscious and bodily communication of wishes and desires which can be facilitated through carers spending time in proximity and participating with individuals with dementia (Wyatt, 2021). This is reflected in the findings that good support looked like staff or family members having empathy, understanding a person’s abilities, interests and communication method, having knowledge of dementia, as well as ‘doing with’ rather than ‘doing for’. The importance of this ‘subtle support’ in tasks and decisions is also documented in the existing dementia literature (Fetherstonhaugh et al., 2013; Giebel et al., 2020).

It is worth noting that more recent literature has challenged the sense of passivity in Kitwood's model, positioning people with dementia as having agency in their social world rather than others bestowing it to them (Birt et al., 2020; Smebye & Kirkevold, 2013). This debate interestingly highlights the interconnected nature of the subthemes of choice, competence and relational connection; that individuals can have choice and competence in their social interactions. In addition to this, the findings of this review suggest that perhaps it is not an 'either/or' of agency or passivity, but rather a 'both/and' (Andersen, 1992); people with intellectual disabilities and dementia can have and demonstrate agency in their social interactions which contributes to maintaining a sense of self, as well as others facilitating and contributing to this.

The three subthemes of choice, competence and relational connection involved in maintaining a sense of self, seem to reflect the well-evidenced self-determination theory (SDT; Deci & Ryan, 1985; Ryan & Deci, 2000). The SDT's three 'basic psychological needs' that support wellbeing and a sense of self are: autonomy (having choice and feeling in control of behaviour), competence (having mastery or skills) and relatedness (having a sense of belonging and connectedness to others) (Deci & Ryan, 1985; Ryan & Deci, 2000) which seem to map onto the subthemes in this review. This goes beyond previous research showing the importance of these three factors for people with intellectual disabilities (Wehmeyer, 2020; Wehmeyer & Avery, 2013) by highlighting their importance for this population even in the latter stages of dementia. The findings give examples of how these needs can be communicated in a variety of ways as verbal ability declines which agrees with SDT which posits that these needs can change in mode of expression, however are universal and persistent (Deci & Ryan, 1985; Ryan & Deci, 2000).

Involving People With Intellectual Disabilities and Dementia in Qualitative Research

A range of methods and adaptations have been used to involve those with intellectual disability and dementia in research, from minor adaptions of simplifying language and adding visual cues to more major methodological choices such as longitudinal observation methods. This mirrors findings in the dementia literature that alternative methodology and increased knowledge can facilitate participation in research (Wilkinson, 2002). Studies did not employ just one adaptation but multiple and therefore the impact of this on researcher time, capacity and resources is not insignificant.

As discussed in relation to carers above, researchers also need to spend time in proximity and participating with individuals with dementia to facilitate a greater understanding of communication that might not be conscious and verbal but unconscious and bodily (Wyatt, 2021). This could be facilitated through longitudinal approaches (Manji, 2008; Watchman, 2013) or through collaboration with carers who can pass on that learnt knowledge. Applying the systemic practice of “well begun half done” (Lang & McAdam, 1996) seems important in this field of research to set up and plan research well.

Strengths and Limitations

The body of evidence in this field is small with a small sample of participants in each study and gathering adequate data a challenge. All the studies took place in English speaking Western countries and of the few that reported ethnicity data, all participants were White. Alternative views and experiences, particularly from different cultures and backgrounds are therefore lacking in the current evidence which is a limitation.

One of the strengths is that the CASP scores suggested a low risk of bias for the included studies. Also, of the participants in the included studies there was a good spread of those both with and without dementia, including those in the latter stages of dementia. The search strategy seemed to be robust, with six studies overlapping with a similar review, with the remaining differences due to disparities in inclusion and exclusion criteria (Jacobs et al., 2023).

The impact of the researcher on the synthesis findings was reduced by carrying out bracketing in a reflexive journal throughout the review process. Carrying out study selection, data collection and the CASP checklists with an independent reviewer improved the consistency of criteria application and reduced risk of errors.

Implications for Future Research and Clinical Practice

There is a small but growing body of qualitative research in this field, however more high quality studies with more participants are required. Future research would benefit from improved reporting, specifically in the areas of reporting sampling methods, demographic data, data analysis and author reflexivity to consider the influence that might have on the research. Further research in non-western cultures is particularly needed.

The intellectual disability and dementia friendly adaptations highlighted in this review should be used, built upon and rigorously tested to improve inclusion of this population in research. This includes collecting non-verbal data through observation or video recording, use of visual prompts, images, large fonts, simple language, and using adaptive communication strategies relevant to the participants. Alternative methods such as nominal group technique are promising but would benefit from a reduced reliance on written communication (Sheth, 2019a). Visual communication aids such as Talking Mats which are often used with dementia and people with intellectual disabilities could help facilitate this (Bornman & Murphy, 2006; Murphy, 2014; Murphy et al., 2010; Murphy & Cameron, 2008). This review found no studies using Talking Mats with this population which would be an interesting area of future research given its encouraging use in similar populations.

In relation to clinical practice, this review highlights the need to discuss dementia with people with intellectual disabilities prior to, during and after diagnosis, supporting current guidelines (Kerr & Wilkinson, 1985; National Collaborating Centre for Mental Health, 2007). This review emphasises the importance of carers facilitating choice, competence and relational connection in order to support the sense of self and wellbeing of a person with intellectual disabilities and dementia, as well as encouraging an individuals' agency in their interactions rather than doing for. People with intellectual disabilities want to be viewed as a human and with a sense of self in the same way that those without intellectual disabilities and/or dementia would also want. Training staff and carers seems to be an important factor in this, particularly around supporting choice and agency in big and small decisions.

Conclusions

This review synthesises the views and experiences of dementia from the perspective of people with intellectual disability. Dementia is associated with loss and transition, maintaining a sense of self is important and support from others facilitates this. This review also highlights that people with intellectual disabilities and dementia can participate in qualitative research with a variety of adaptations. However research in this area is limited by the small amount of research and a lack of ethnic and cultural diversity. Future research should seek to adopt the highlighted adaptations to improve participation in research for this population.

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Part 2: Empirical Paper

The Adaptation of Group Cognitive Stimulation Therapy for People With Intellectual Disabilities who Have Developed Dementia

Abstract

Aims

Cognitive Stimulation Therapy (CST) is an evidence-based, group intervention for dementia. It is being delivered in some clinical services for people who have intellectual disabilities and dementia. However, local practice has varied and evaluation has been challenging. The aim of the study was to develop a supplement for the standard CST manual to support delivery of adapted CST for people with intellectual disabilities and dementia (CSTIDD).

Method

A four-phase qualitative adaptation approach was taken to adapt CST to people with intellectual disabilities, following the ADAPT framework for adapting interventions to new contexts. Stakeholders provided input on the adaptations including carers delivering individual CST (phase 1), health professionals with experience of working with people with intellectual disabilities and an expert by experience with intellectual disability (phase 2) and a clinical research group who coproduced a CST adaptation for people with intellectual disabilities and dementia in collaboration with carers (phase 3). CSTIDD was piloted (phase 4) and qualitative feedback gathered from one participant, one carer and two group facilitators using interviews and Talking Mats and the CSTIDD manual supplement created.

Results

Stakeholders highlighted the importance of facilitator awareness of issues that pre-dated dementia onset such as sensory sensitivities, low literacy and early trauma. Stakeholders also provided suggestions for additional activities and adaptations. CSTIDD was piloted and group participants, carers and facilitators were positive about the intervention. Interviews and a Talking Mat generated valuable qualitative data.

Conclusions

CSTIDD is a promising intervention for people with intellectual disabilities and dementia. Further research will examine the acceptability and feasibility of it.

Accessible Summary

- Cognitive Stimulation Therapy, called CST, is a group activity for people who have dementia.
- This research changed CST to make it fit for people who have intellectual disability and dementia.
- The researchers asked people with intellectual disability, carers and healthcare professionals what they think about CST.
- A booklet was made to help health professionals run CST.
- More research will find out if CST is helpful for people with intellectual disability and dementia.

Introduction

Intellectual Disabilities and Dementia

As the intellectual disability population grow older, prevalence of dementia is increasing (Sinai et al., 2012; Strydom et al., 2013). People with intellectual disabilities are more likely to develop dementia and develop it at an earlier age (Mccarron et al., 2014; Takenoshita et al., 2020), yet research is lagging behind (Kirwan et al., 2022; Sheehan et al., 2014). Further research in this area has been recommended, particularly the adaptation of psychological interventions for dementia for use with people with intellectual disabilities (The British Psychological Society, 2015).

A recent review of psychosocial interventions for this population identified a number of interventions with largely positive outcomes, though limited by small sample sizes (MacDonald & Summers, 2020). Therapeutic interventions directly with the individual(s) with intellectual disabilities and dementia included music oriented groups, memory cafes, dementia support groups and life story books/rummage boxes. Positive outcomes of these therapeutic interventions included pleasure and enjoyment for the individual, social and communication benefits, improvements in affect, wellbeing and quality of life. However, it was noted that poor methodological rigour impacted these findings and that Cognitive Stimulation Therapy (CST) had not yet been adapted despite the recommendation to adapt existing interventions for dementia (The British Psychological Society, 2015).

Cognitive Stimulation Therapy

CST is a brief, manual based, 14 session treatment for people with mild to moderate dementia (Spector et al., 2020). It is usually delivered in groups and involves different themed activities aiming to engage and stimulate people with dementia. It is evidence-based, with it shown to improve quality of life, general cognitive functioning and language comprehension and production (Lobbia et al., 2018) and is the main non-pharmacological treatment recommended by the National Institute for Clinical Excellence (NICE) for cognition, independence and well-being in the general dementia population (NICE, 2018).

Another recent review (Dennehy et al., 2022) identified that individual CST (iCST) adapted for people with intellectual disabilities and dementia in a feasibility randomised control trial (RCT) is feasible and acceptable (Ali et al., 2022). iCST for intellectual disabilities seems promising, however there is much stronger evidence for CST in dementia (without intellectual disabilities) when delivered in a group format (Sun et al., 2022). Group interventions are also more cost-effective and therefore more feasible to implement in the NHS.

A community intellectual disability service ran an adapted version of CST and generally found positive outcomes, however it was a case study design with a lack of data analysis methodology (Jervis et al., 2021). The same paper referenced another team who also adapted CST and piloted it. Also, during the process of this project, a paper outlining the co-produced adaptation of CST for intellectual disability and dementia was published (Acton et al., 2022). It therefore appears that CST is being delivered to people with intellectual disabilities and dementia in some settings, but not in a uniform way and with no formal manual or evaluation, making it challenging to assess feasibility or compare outcomes. There is therefore a need to standardise an adaptation of CST for people with intellectual disabilities and dementia and evaluate it more rigorously.

Adapting Therapies

Guidelines for adapting CST (Aguirre et al., 2014) follow the formative method for adapting psychotherapy (FMAP; Hwang, 2009). However, more recently, the ADAPT framework for adapting interventions to new contexts (Moore et al., 2021) was developed as part of a project funded by the UK Medical Research Council and National Institute for Health Research (NIHR) to improve the process and reporting of intervention adaptations (Evans et al., 2019). Different approaches, including FMAP, were drawn together and consolidated into a framework involving four steps with the overarching principle to include a diverse range of stakeholders in the whole process (Moore et al., 2021). Step one assesses the rationale for the Intervention, with adaptations planned and undertaken in step two.

Piloting and evaluation is planned and undertaken in step three with the final step to implement and maintain the adapted intervention at scale.

Adaptions of interventions should include public and patient involvement (PPI, Moore et al., 2021). However, as highlighted in part 1 and the literature, it can be challenging to involve people with intellectual disabilities and/or dementia in research due to factors including cognitive capacity, gatekeeping of carers and organisations, and the extensive work and consideration needed to do this well (Di Lorito et al., 2018; Waite et al., 2019). Previous adaptations of psychosocial interventions for people with intellectual disabilities and dementia have often used pilot studies to test out adaptations, gathering PPI feedback during or the end of interventions; this has included gathering feedback from staff and/or carers (Bevins et al., 2015; Jervis et al., 2021; Kiddle et al., 2016; Ward & Parkes, 2017; Watchman et al., 2021), feedback from intervention participants (Jervis et al., 2021; Kiddle et al., 2016; Ward & Parkes, 2017), using quantitative measures (Crook et al., 2016; Jervis et al., 2021; Kiddle et al., 2016) and feedback from co-researchers with intellectual disability without dementia (Watchman et al., 2021). However, gathering feedback during or after a pilot intervention only addresses step three of ADAPT and misses the adaptation in step two. One study reported that the intervention was adapted by professionals prior to piloting (Jervis et al., 2021), other studies did not report this information, except in the case of Acton and colleagues (2022) who co-produced their adaptation with six carers of people with intellectual disabilities and dementia.

Aims

This study aims to adapt CST for people with intellectual disabilities and dementia following the ADAPT framework and involving PPI at each stage by:

- Multiple stakeholders giving views of CST through carer diaries, interviews and focus groups.
- Producing a supplement to use in conjunction with the main CST manual (CSTIDD).
- Piloting the delivery of CSTIDD and gathering feedback from group participants with intellectual disabilities and dementia, carers and facilitators.

Methods

Study Design

A four-phase qualitative study was conducted to adapt CST for people with intellectual disabilities and dementia. Phases one to three took place between January 2022 and October 2022 and involved gathering feedback on CST from stakeholders. The fourth phase was a pilot of CSTIDD and took place between June 2022 and May 2023 with the purpose of testing the intervention adaptation.

This adaptation sits within a planned NIHR funded feasibility RCT to adapt and test CSTIDD (Ali et al., 2023). This paper summarises the first part of the RCT; to adapt the intervention. Phase four of this adaptation is treated as an ‘internal pilot’ delivered within the feasibility RCT, with data contributing to the adaptation as well as being included in the wider feasibility RCT (Charlesworth et al., 2013). Quantitative methods will be used in the wider RCT to evaluate feasibility and acceptability of the intervention however this is outside the remit of this thesis which was to focus on the adaptation of the intervention itself. Another trainee, Cheryl Francis, was also involved in the wider project; the contributions are outlined in Appendix B.

Ethics

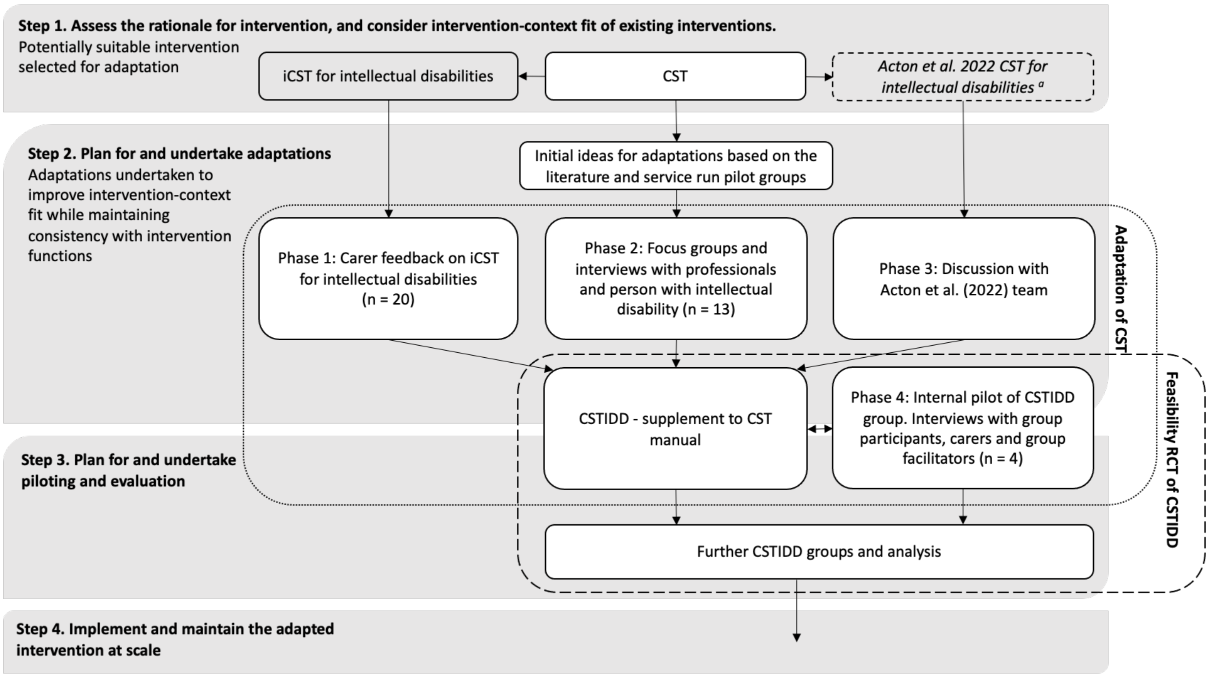
Ethical approval was granted by the East of England Ethics Research Committee (reference number: 21/EE/0247) and Health Research Approval was granted; see Appendix C and D respectively. Anonymised data from the iCST trial (reference number 17 LO/0030) was used with permission from Ali who was also involved in the adaptation and feasibility RCT.

Framework for Adaptation

The ADAPT framework was followed (Moore et al., 2021). Step one is outlined in the introduction; this paper primarily focuses on step two, the adaptation of CST. The CSTIDD pilot contributes to the adaptation however is also part of the feasibility RCT which aims to pilot and evaluate CSTIDD. Therefore it crosses steps two and three of ADAPT, outlined in figure 1.

Figure 1

Diagram of How This Adaptation Maps Onto the Four Steps of ADAPT and Links With the Feasibility RCT



[a] Acton et al. (2022) not identified in Step 1 as published while in the process of step 2. However incorporated into adaptations.

Adaptation Process

The second edition of the group CST manual (Spector et al., 2020) was the foundation of the adapted intervention. Initial ideas for adaptation were formed from the literature and experiences of the project research assistant who had piloted an adapted intervention in an intellectual disability service. It was planned that a supplement to the main CST manual would be created, rather than a new manual, in order to maintain the core integrity of the intervention in alignment with ADAPT (Moore et al., 2021) while providing flexibility for necessary adaptations.

Phase 1: Input From Carers

Input on CST from the perspective of carers was collected from those who participated in the iCST trial (Ali et al., 2022). These family and paid carers had experience of caring for someone with intellectual disabilities and dementia as well as experience of running CST activities with them so could provide valuable insights. After completing each iCST activity, carers completed qualitative diaries asking if there was any way to improve the activity and for any other comments. A mapping exercise was undertaken to identify which of the 40 iCST sessions included activities relevant to the 14 sessions in group CST. Diary entries of those relevant sessions were analysed.

Phase 2: Input From Professionals and a Person With Intellectual Disability

Healthcare professionals experienced in working with people with intellectual disabilities gave input on CST through three focus groups and one interview. Feedback from an individual with intellectual disability (without dementia) was collected in an interview. They took part in-person and online via Zoom videoconferencing software and were recorded and transcribed. During the focus groups and interviews a brief introduction to CST, the themes and potential activities were given and those participating were invited to share comments, feedback and ideas.

Phase 3: Input From Cheshire and Wirral Research Group (Acton et al., 2022)

While carrying out the above phases, a multi-disciplinary team consisting of one clinical nurse specialist, two occupational therapists and one psychiatrist, which will be referred to in this chapter as the Cheshire and Wirral research group (CWRG), published their adaptation of CST (Acton et al., 2022). This was co-produced with six paid and family carers with at least two years of close contact with a person with intellectual disabilities and dementia. Members of the CSTIDD research team (research assistant and co-principle investigator) had a series of discussions with the CWRG to combine their findings with phase 1-2.

Phase 4: CSTIDD Pilot and Feedback From Group Participants, Carers and Facilitators

A CSTIDD pilot was carried out to test the intervention and gather further input on adaptation. Feedback was sought from group participants with intellectual disability and dementia, their carers, and those that facilitated the group, in the form of semi-structured interviews after the CSTIDD group. This group was delivered within the feasibility RCT; inclusion and exclusion criteria are found in table 1; further details are in the trial protocol (Ali et al., 2023).

Table 1

Eligibility Criteria for Group Participants

Inclusion Criteria	Exclusion Criteria
1. Premorbid mild or moderate intellectual disabilities (based on clinical notes) 2. Aged 18 and over. 3. Clinical diagnosis of mild or moderate dementia based on service records 4. Ability to provide informed consent or (if the participant lacks capacity) availability of a consultee who has agreed to participation in the study. 5. Ability to communicate in English	1. Significant visual or hearing impairment that may interfere with participation. 2. Significant physical illness or disability, affecting ability to attend groups. 3. Significant behavioural problems that could affect participation (e.g. aggressive behaviour).

It was planned to carry out interviews at the end of the final CSTIDD session. However, as this was cancelled, interviews were arranged through carers by phone. Group facilitators and carers of those in the group were invited by phone or email to take part in interviews after the intervention.

Consent and Ethical Considerations

Written consent to take part in the group and optional interviews was given by group participants. Where participants did not have capacity, participation was discussed with personal or nominated consultees who signed declaration forms if they felt the participant would want to take part. Following findings from part 1 about ongoing consent, the author checked consent to participate at the start of the interview and paid attention to non-verbal cues that might communicate this. Carers and group facilitators who wanted to take part in interviews also gave written informed consent. Information sheets and consent forms can be found in Appendices E to N.

The author considered and discussed how to get the balance between data collection and participant burden with the CSTIDD co-principal investigator, given the cognitive difficulties of the population. It was agreed to conduct one short interview at the end of the final session, as it was felt that doing this after multiple sessions would be overburdensome for participants, despite the potential benefit to gather more valid data.

Data Collection

Carers and group facilitators took part in semi-structured interviews over the phone or Microsoft Teams videoconferencing software. Group participants were interviewed in-person using a Talking Mat methodology (Murphy, 1998). All interviews were audio recorded and transcribed and a picture of the Talking Mat was taken.

Interview Guidelines

Interview guidelines were similar but differed slightly between type of interviewee. Carers and facilitators were asked about their experiences as well as the participants' experiences of the group. Questions also addressed how the activities and supplement worked in practice (see Appendix O and P).

As identified in part 1; the use of visual communication methods can support the inclusion of participants with intellectual disabilities and dementia in research. Talking Mats, which use pictures to structure and facilitate conversations, are a good example of this. The mats have a topic and a top scale which are flexible. The topic used for this research was 'CST group' and the top scale was 'like', 'unsure', 'don't like'. The participant was given cards one at a time that had a picture and word on to correspond with open ended questions, for example "how did you feel about the group quiz?" The participant then placed the card on the mat where they chose (see Appendix Q). Cards were presented in similar groups and moved from more concrete to abstract ideas. The opportunity to add other cards or move cards was given and follow up questions asked for example "what did you like/not like about the quiz?" A 'starter topic' was used before the main Talking Mat, which involved the same process but with more concrete questions. This introduced the process to the participant and checked their understanding; if they did not understand the starter mat, the full mat was not attempted.

To aid orientation and recall, it was planned to interview group participants straight after the final session and in the same location as the CSTIDD group. The final session was cancelled due to adverse weather so the interview took place at their home. The group name and group song used in the CSTIDD group were used in the interview to aid recall. Photosymbols and Picture Exchange Communication System (PECS) symbols were available depending on what the participant most used and images that were used in the group and in the trial materials were also used to facilitate comprehension through consistency. Images and text were printed in large scale/font to aid accessibility. These can be found in Appendix R.

The Talking Mat methodology used for this interview was developed and discussed in collaboration with key stakeholders including professionals with experience working with people with intellectual disabilities and dementia and with a person linked with the trial with intellectual disability (without dementia). Attempts were made to include a wider group of people with lived experience of intellectual disability and their carers in the development of the methodology but this was not possible to complete in the timescale.

Data Analysis

Phase 1 and 2: Input From Carers, Professionals and a Person With Intellectual Disability

Phase 1 data (from carer diaries) and phase 2 data (from focus groups and interviews) were entered into a Microsoft Excel spreadsheet and analysed using Qualitative Content Analysis (Mayring, 2000). Qualitative Content Analysis was a good fit as it considers both latent and manifest content and uses both inductive and deductive approaches (Drisko & Maschi, 2016). Content relating to specific adaptations to sessions was approached deductively with each session a specific category and suggestions identified within each one, pertaining to more manifest content. General adaptations were approached more inductively and included more latent content.

Phase 3: Input From CWRG

Recommendations from Phase 1 and 2 and those from the CWRG were tabulated to facilitate comparison of the two approaches and analyse for similarities and differences.

Phase 4: CSTIDD Pilot and Feedback From Group Participants, Carers and Facilitators

Phase 4 provided an opportunity to hear the experience of delivering or attending CST groups for people with intellectual disabilities and dementia and gain insight into the adequacy of adaptations. Narratives were compared to findings from the previous phases, with similarities and differences noted. This included noting findings related to the suitability of specific activities themselves and the manual as a means of facilitating that, as well as the wider practical aspects of running the group that were recommended from phases 1-3.

Author Description

The researcher is a white woman in her mid 30’s with substantial experience working with older adults, including people with dementia and their carers, and experience working with people with intellectual disabilities. The researcher is trained to facilitate CST and has experience of doing this with people without intellectual disabilities and has foundation level training in the use of Talking Mats.

Results

Results From Phase 1 and 2: Input From Carers, Professionals and a Person With Intellectual Disability

Phase 1 Carer Characteristics

Twenty carers provided written feedback on the sessions. Carers had an average age of 49.5 years, were mainly female (75%), 55% of White ethnicity and 75% paid carers (see table 2).

Phase 2 Characteristics

Thirteen stakeholders took part in the consultation process across three focus groups and two interviews comprising of 12 professionals and one person with intellectual disability (without dementia). All professionals had experience of working with people with intellectual disabilities and some had experience of CST or iCST (see table 3). One professional joined focus group 1 however had technical issues so joined the second focus group to be able to contribute more fully. Unfortunately focus group 3 was not audio recorded so notes taken from feedback were entered into the spreadsheet instead.

Table 2

Demographic Information of Carers in Phase 1

Demographic Information	Number / Age in Years
Average age of carer (SD)	49.5 (14.7)
Gender of carer:	
Female	15 (75%)
Male	5 (25%)
Ethnicity of carer	
White British	11 (55%)
Other	9 (45%)
Relationship to participant	
Relative/ Friend	5 (25%)
Paid carer	15 (75%)
Average years of experience as a carer (SD)	14.2 (21.4)

Table 3

Profession and Experience of Those in Focus Groups and Interviews

Meeting	Profession / Role	Experience
Focus group 1	Psychologist [a]	• Working with people with intellectual disabilities • CST for people with dementia without intellectual disability
	Occupational Therapist	• Working with people with intellectual disabilities • iCST for people with intellectual disabilities
	Nurse	• Working with people with intellectual disabilities • iCST for people with intellectual disabilities
	Speech and Language Therapist	• Working with people with intellectual disabilities
Focus group 2	Psychologist [a]	• Working with people with intellectual disabilities • CST for people with dementia without intellectual disability
	Psychologist	• Working with people with intellectual disabilities • CST for people with dementia without intellectual disability
	Occupational therapist	• Working with people with intellectual disabilities
Interview 1	Occupational Therapist	• Working with people with intellectual disabilities

		Group CST for people with dementia and intellectual disabilities
Interview 2	Person with lived experience linked with the trial	Lived experience of intellectual disability Knowledge of dementia and CST
Focus group 3	Psychologist	Working with people with intellectual disabilities Attended main CST training but not run
	Psychologist	Working with people with intellectual disabilities Attended main CST training but not run
	Occupational therapist	Working with people with intellectual disabilities Attended main CST training but not run
	Occupational therapist	Working with people with intellectual disabilities Attended main CST training but not run
	Psychiatrist	Working with people with intellectual disabilities Attended main CST training but not run

[a] This psychologist was present in focus groups 1 and 2 due to technical difficulties

Phase 1 and 2 Qualitative Content Analysis

Content Analysis findings from phases 1 and 2 are presented in table 4 along with recommendations for the adaptations as a result of these findings. There were many positive comments from carers who discussed adapting activities by rephasing, simplifying questions or activities or using materials of interest for example magazines or CDs. Carers also noted how mood affected an individual’s engagement and how interest was lost when activities were too difficult, which sometimes led to frustration or agitation in 3 individuals. As well as general feedback, carers made recommendations about specific activities (see table 4).

Professionals and the individual with intellectual disability were also positive about CST, offering general recommendations such as use of easy read, comments about the practicalities such as number of facilitators, and specific recommendations for activities (see table 4).

Results From Phase 3: Input From CWRG

Table 5 outlines similarities and differences between phase 1 and 2 recommendations and those of the CWRG. Keeping the original session length (45-60 minutes) and number of facilitators (two) and ensuring carers have adequate information about CST was recommended by both.

The CWRG altered the order, names and focus of sessions which differed from phase 1 and 2; this was not carried over to this CSTIDD adaption in order to retain the integrity of the original intervention in alignment with ADAPT (Moore et al., 2021). The resource to facilitate activities between sessions was also not carried over as this departs too greatly from the original intervention. Some activity ideas overlapped and others differed, therefore some of the ideas from the CWRG were incorporated into this adaptation to offer greater variety of choice to facilitators, given the need to adapt to ability and interest highlighted in phase 1 and 2.

Table 4

Qualitative Content Analysis of Carer Feedback, Focus Group, and Interview Data and Recommendations.

Categories	Individual CST	Examples	Focus Groups and Interviews	Examples	Actions
Warm up introduction	Not applicable	Not applicable	Use visual timetable with consistent images (4) Follow easy read guidance (2) Tailor to interests (3)	“keep it consistent so either Makaton, or signs, or photographs, either one or the other.” I1 Do an easy read standard so they all look the same, so one idea and one sentence per line... And Photosymbols is good for defining the pictures as well” FG2 “Adapting it to the group, who’s coming and what they would prefer.” I1	• Tailor options to interests • Use visual aids for timetable and keep consistent • Use easy read news if interested
Session 1: Physical Activities	Physical activities were generally enjoyable (14) - Throwing or rolling games were enjoyable (8) - They could be done seated (2) Some found them not enjoyable or too difficult (4)	“Played table top tennis. Stimulating and fun and physical. Participant was very engaged.” Carer 4 “(Participant) enjoyed catching / throwing the balloon. She found it funny when it kept falling to the floor.” Carer 16 “Loved playing skittles. Has a very strong throwing arm. All done from sitting in her chair. Laughed throughout” Carer 20 “Unable to do physical activity because of mobility problem.“ Carer 14	Adapt the activities to ability (9) Do a risk assessment (1) Focus on the effort rather than the outcome (1)	“it's about grading it to the to the level of who you've got” FG1 “do a risk assessment beforehand” FG1 “is it just a movement or is it actually trying to get the ball in the right place because if they couldn't do that before then it doesn't really tell you anything” FG2	• Physical activities seem appropriate to include • Detail importance of adapting activities to the physical ability of the group and give examples. Give some examples e.g. skittles, or doing it sitting or standing. • Mention importance of risk assessment • Focus on the effort rather than outcome (similar to principles in main CST manual)
Session 2: Sound	Listening to sounds and matching them to pictures was enjoyable to some (6) This same task was not enjoyable or was too difficult for others (7)	“(Participant) enjoyed the activity, liked to make sounds, also to find out which sound belongs to which animal/subject” Carer 7 “The participant did not appear to enjoy this greatly but I feel others would enjoy the activity nevertheless.” Carer 4 “She was agitated and confused as to where the sounds were coming from” Carer 5	Grade the activity depending on ability (3) Need to be aware of auditory sensitivities (1) Using TV theme tunes as sounds (1)	“You could have three choices or two choices (of pictures to match with the sound)” FG 2 “Some people may have auditory sensitivities or not like the sound of certain things” I1 “TV theme tunes might be better than pop songs or radio jingles…then you can tie it up a bit more easily with pictures…Eastenders, Coronation street are popular ones.” FG 2	• Listening to and identifying sounds can be included but need to highlight other options if too challenging. • Offer options for grading • Highlight need for aware of sensory sensitivities

Categories	Individual CST	Examples	Focus Groups and Interviews	Examples	Actions
Session 3: Childhood	Enjoyed /engaged well in talking about childhood and things related to childhood (10) Some found talking about childhood and things related to childhood challenging (9) However photos of people were helpful prompts (6)	“Enjoyed talking about personal life” Carer 15 “(Participant) does not remember much of her childhood and youth, so some questions are hard for her to answer” Carer 7 “They interacted better with photos to look at instead of just asking about family and events. At times unable to answer, remember but then start talking.” Carer 4	Be mindful of potential past trauma (5) It is beneficial to talk about memories (6) Knowing the group and being sensitive to their experiences can help with managing potential trauma experiences (4) Adapt the form using picture prompts (2)	“(some people) had quite traumatic experiences of living with the family so again it's about, as you say, knowing the group and knowing the individuals in the group” FG 1 “I don't think to remove it all together, I think it would still be really valuable...it's just being sensitive isn't it if the trauma” I1 “maybe try to have the form with some picture prompts… because some people might be able to tell you the information on the form, but just with a bit of prompting… (for example) when you were five what was your favourite food, or like things that are more specific, direct questions.” FG2	• Still include a childhood session but mention to be mindful of childhood trauma • Ask participants to bring in photos to facilitate this session • Adapt the form to make a page with picture prompts of potential things people can choose to talk about.
Session 4: Food	Enjoyed / interested in talking about food and related activities (11) Difficulty or lack of interest in talking about food and related activities (3) Talking about ingredients was not interesting or too challenging (5) The way that food was presented either the photo quality or if in packaging or not affected ability to recognise (3)	“(Participant) identified all types of food apart from some sea foods. Assisted in making a strawberry smoothie. Very suited exercise, appears to have enjoyed a lot.” Carer 18 “(Participant) did not seem as interested with this activity as she has done with the others. Only small inputs and a lot of verbal prompt given.” Carer 10 “Tried but could not talk much about the ingredients for recipes.” Carer 14 “Did not recognise everyday items - maybe due to packaging. Used reference book with photos of food / drinks appropriate to age - more successful! Used food images - not very clear.” Carer 20	Being hands on with food (4) Using food packaging (1) Making use of the texture of food (1) If bringing food to the session need to be aware of dietary needs, dysphagia and sensory sensitivities (3)	“Talking about making something is a bit abstract one as it's removed from what's actually happening... They can make like a fruit salad or something that doesn't require much you know actual cooking or sharp implements, it might spark off more conversation if they're actually preparing it.” FG2 “I think that's really good to have the packages of food as an object reference” I1 “being able to feel what piece of bread feels like or a piece of jelly what that feels like or, to put your hand in in something…so you have those different textures not necessarily taste of putting in your mouth”. FG1 “You would have to consider a lot of the dietary things and dysphagia” FG2	• Avoid talking about ingredients and meal planning • Bring in food if possible • Include sensory aspects of the food such as taste, touch and smell • Alternatively bring in food packaging • Check for any swallowing difficulties or dietary needs.
Session 5: Current Affairs	Able to recognise famous faces and discuss (9) The Queen and the royal family was most known (5)	“The resident chuckled when he recognised the people. An enjoyable 1/2 hour. We recognised singers, royal family, arsenal football team.” Carer 2 “(Participant) struggled to recognise the people in the images. This may be why she showed little interest”. Carer 10 “(Participant) recognised the members of the royal family, but other subjects are out of her interest. Instead we took a	Using alternative media like video clips and social media (2) Using easy read (1) Use news from people’s own lives or interests (2)	“If you're a small group you could look at the internet and YouTube's and stuff to help them to express a little bit more maybe...what's trending on TikTok.” FG1 “make it easy read for starters, with as you say your own stories for the news section would be brilliant” I2	• Ensure news story /people of discussion are known and of interest to the group • Offer easy read news option • Use alternative media

Categories	Individual CST	Examples	Focus Groups and Interviews	Examples	Actions
	Unable to identify or therefore discuss any of the famous faces (5) Need to adapt people to interests (5) by looking at CD covers, TV magazines, photos and online	look at her TV magazine and as she likes to watch soaps, we talked about those characters and what is happening to them - that was much more of an interest to her." Carer 7			
Session 6: Faces and Scenes	Able to identify and discuss some scenes (10) Not interested or able to discuss scenes (11)	"Showed a lot of interest in identifying difference scenes, spoke of this holiday to Italy when he was shown picture of waterfall." Carer 18 "(Participant) had no knowledge or any interest in (looking at scenes)" Carer 14	Tailoring to the experiences, interests and culture of the group (6)	"a picture of a famous mosque might be more appropriate when you're talking about famous places, but then churches might be for others" FG2 "People in borough A wouldn't go into London, or people in borough A wouldn't go into borough B so again it's really about responding to the group." FG1	• Try to have people and places that you know participants know/have visited
Session 7: Word Association	Enjoyed and was able to match phrases/places/couples (4) Was unable to make matches between phrases/places/couples (4)	"Enjoyed the whole activity. Was able to match phrases and change a few. Needed prompts for places/couples." Carer 4 "The pictures proved difficult for (the participant)" Carer 1	Proverbs too complex (2) Finish the song activity (3) Tailor to the groups' interests (3) Use of pictures (2) No right/wrong answers, there could be multiple matches (1)	"I think people might get confused with the proverbs." I1 "to me (finish the song) is a brilliant way of getting them involved… you could try that with Disney songs…you could put up a picture of a Disney character and you could sing along." I2 "From session one you'd have an idea of what their [music] tastes are so you could pick from there." FG2 "The use of the pictures will take that pressure off them having to think in that way" FG1 "it may not be what everyone else is seeing is the same idea so maybe somebody might have chicken and chips and fish and chips me yeah I'm sort of accepting that as well. FG1	• Don't use proverbs • Use images rather than written words • Finishing song lyrics to familiar songs • Base on interests • No right or wrong answers already part of the main CST manual
Session 8: Being Creative	Found the art discussion too difficult or uninteresting (7) Enjoyed the art discussion (3) Enjoyed the creative activity (8) (these were a variety of practical creative activities chosen by the carers and participants)	"(Participant) found it hard to talk about the activities…she had no interest." Carer 6 "(Participant) enjoyed talking about the pictures" Carer 10 "(Participant) chose to paint a face mask. She really enjoyed this activity" Carer 5	Consider whether additional support required (2) Not many adaptations needed (2)	"whether they need to sit down or physical assistance or whether they might be a safety risk with using scissors or consumable items". I1 "I agree that no particular adaptations needed" FG2	• Discussion about art may not be suitable – would need to adapt to interests of group e.g. Bake off. • Practical creative activities fit well. • Suggest activities that can be done sitting

Categories	Individual CST	Examples	Focus Groups and Interviews	Examples	Actions
	Not interested in the creative activity (1)	“Danced with me from her armchair laughing loudly. Enjoyed watching seed sowing, watered plant pots” Carer 20 “Not his flavour today as he does a lot of this at day centre” Carer 9			
Session 9: Categorising Objects	Interest in identifying the pictures (10) Not able to categorise/complete odd one out with the pictures (9)	“(Participant) is always pleased to work with pictures, it makes it easy for her to start the conversation. She would talk about the individual pictures, identified groups such as fruits, meat, vegetables or animals. Also bus and taxi.” Carer 7 “Discussed the items in the pictures but could not point out the odd one out. However spoke a lot about each picture and showed a lot of interest” Carer 18	Use small number of pictures to categorise (3) Or use objects to categorise (1) Make a collage (1)	“maybe just having the pictures with the words and then they categorise it. The same pictures can be in different categories and they can play a game with it.” FG2 “it would be good to get actual objects, but obviously you would need masses of them” FG1 You could make it into a creative thing like a collage or something…it will give them a visual activity and a creative one as well. I2	• Naming words beginning with letters may be too difficult • Work with a small number of pictures/objects at a time • Could make a collage • Odd one out game
Session 10: Orientation	Not able to complete or not interested in the orientation activities (11) Able to take part in the orientation activities, particularly use of photos (7)	“They knew where they were born but didn't know anything about the map or where to find it. Didn't seem interested about the map.” Carer 4 “(Participant) was very excited and happy to talk about the places in the book. She recognised many of them and showed enjoyment, through talking, leading to her talking about her own experiences of (country of birth).” Carer 15	Map might be too challenging unless simple and adapted (4) Talk about the local area where they live/lived (5) Orient in relation to interest or holidays (2) Look at seasons or festivals (1)	“the concept of maps might be quite challenging … using maps, and maybe looking at some of the more famous buildings and trying to match which country they might come from as an idea that might help” FG1 “you could just do the area or borough in which they lived.” FG2 “A holiday could be quite good, ‘cause you could say "oh I've been on holiday to Turkey” I2 “maybe looking at things like seasons and festivals, and when they would actually be in the year” FG1	• Geographical locations may be too difficult – adjust for ability • Discuss where live • Discuss time of year • Discuss places visited with map only if suitable • Bring photos to discuss
Session 11: Using Money	Identified and recognised the coins (8) No understanding of the value of money (3) Not able to carry out the money activity (4)	“(Participant) recognised a pound coin and the five pound note in the activity. He is fully aware that money can be spent on purchasing items but does not have an idea of their actual worth” Carer 17 “(Participant) has no understanding of money, it's value or usage. I tried to adapt the activity to make it simpler but he lost interest very quickly.” Carer 13	Concept of money might be too complex (3) Could discuss what they would like to buy (3) Have items that participants could ‘buy’ with pretend money (3) Ask what is more expensive (2)	“if somebody with a mild learning disability would more than likely have some difficultly with money anyway, and then plus having the dementia, I think it may be too challenging.” I1 “it'd be more about their wants and desires, rather than how much the cost” FG1 “using fake coins or money or realistic notes then a few items with a price on them. You have a £20 note and ask what can you buy with that money?” FG2 “having different objects and which one, do you think would be the most expensive so that they can do a comparison of it, would a bar of	• Value of money might be too abstract • Have pretend money/pictures for group to identify • Ask what people like to buy • Ask what costs more between two items • Have items the group can buy with pretend money

Categories	Individual CST	Examples	Focus Groups and Interviews	Examples	Actions
				chocolate be more expensive than a handbag?” FG1	
Session 12: Number Games	The number games were enjoyable (11) - Snakes and ladders enjoyable (3) Not able to or not interested in number games (9)	“Good interaction between participants during snakes and ladders, good fun!” Carer 4 “She enjoyed playing snakes and ladders. I made different sounds when we went up the ladder and down the snakes. She managed to play for 30 minutes before becoming distracted.” Carer 5 “(Participant) would not be able to complete the activity by the instructions as she has no knowledge of numbers” Carer 7	Use larger version games (3) Try bingo (2) Appropriate games (1)	“they do a version for people living with dementia, which have got much bigger squares on them fewer ladders fewer snakes and rather than a dice cards that you take, so I think just using some of the adapted games would make this more accessible.” FG1 “What about something like a number bingo?” I2 “I think that's quite important to bear in mind as well is the dignity of the person, that we are not taking the person back to school, we're playing a game that they might have played in the past (snakes and ladders and dominoes).” FG2	• Use large versions of games • Snakes and ladders, dominoes or bingo
Session 13: Word Games	Don’t understand the concept of rhyming (6) No interest or understanding of the alphabet (5) Have partial or good knowledge of the alphabet (2)	“he does not understand words that rhyme although we did give it a try” Carer 13 “(Participant) does not seem to know the alphabet and therefore not able to identify which letters link to object/animals, was not able to do wordsearch.” Carer 15 “Knew A-G of alphabet.” Carer3	Story cubes (3) Letter soup game (1) I went to the market game (1)	“that's brilliant (story dice), that would turn into quite a creative story…rolling a dice with pictures on would make it more visual…really help people with disabilities.” I2 “Letter soup…you would have the word and they would have to find (the letters)” FG2 “I went to the supermarket and I bought… not to remember it all but just link the items with one letter of the alphabet” FG2	• Spelling and crosswords likely too difficult • Story cube game • Letter soup game – pick letters out of a bowl to match word on the table • I went to the market game
Session 14: Team Quiz	Enjoyed the visual and sound quiz games (7) Not able to complete the games (5)	“They were extremely interested in the quiz. Knew all the missing words and could sing along.” Carer 4 “She could only recognise the pictures of some of the animals, but showed little interest otherwise. Was distracted by activities around her.” Carer 14	Failure free quiz (2) Bring in interests and activities that the group have enjoyed over the sessions (2) Having a sound and visual quiz (2)	“you don't want make it too easy, because that would feel patronizing and simplistic wouldn't stimulate people enough, and you don't want to make it so difficult but they feel like a failure.” FG2 “it's also kind of bringing in a bit of everything that you've done over the last 14 sessions, so you could pick out the bits that really worked well and then put them together” FG1 “That visual and sound adaptation sounds perfect” I1	• Simple quiz based on interests • Visual/sound quiz • Have a party

Categories	Individual CST	Examples	Focus Groups and Interviews	Examples	Actions
			Have a party (1)	“it's always good to have a party at the end” FG1	
Other general adaptations	iCST activities were enjoyable for participants (87)	“He really enjoyed this one…the whole lot.” Carer 9	Two sessions in a day would be too much (4)	“I think two sessions in one day might be exhausting for the person” FG1	• Adapted activities like the ones in iCST are appropriate for this population • Suggest different activities for different abilities and interests in line with existing advice in manual • Two sessions a week on different days in line with the original manual • Need to have at least two facilitators in line with the original manual • Ensure carers have information about CST • Carers could attend the groups
	Carers recommended adapting the activities to ability and interest (7)	“Each activity should be made to the interest of the person.” Carer 6	Two sessions in a week would be ok (3)	“if it's possible to do twice a week over seven weeks that is amazing because we know that's what works.” FG2	
			Busy timetables might be a barrier to being able to meet twice a week (2)	“the only other thing is they have quite a bit of a structured timetable, full of other activities going on. That might be a challenge going twice a week...but if it's if for a health need you know it's a health intervention isn't it so I'm sure that carers would prioritise it” I1	
			Giving participants and carers information about the group or taster sessions (2)	“Tell them all about it…explain what activities there are going to be on those two days a week…then they might think ‘Oo those sound interesting I'd like to join.’” I2	
			Need to have at least two facilitators (4)	“I think it would need two (two facilitators) it’s hard to keep track of what is everyone is doing the whole time with one person, and having another set of eyes there is really helpful.” FG2	
			It could be helpful for carers/family members to be there (4) to offer support and continue the learning	“If the support worker is there, maybe they can prompt and also once the group is finished, they can keep the good work going.” FG2	
			Keeping cost of resources low by using laminated pictures (3)	“I’m just thinking of resources in trying to not have huge cost implications… you know, laminated pictures of individual bits of food that people can actually put onto a card to make up a meal” FG1	

Table 5

Comparison of Recommendations Between Phase 1 and 2 of This Paper and CWRG (Acton et al. 2022)

Area of CST	Phase 1 and 2 Recommended Adaptations	Cheshire and Wirral Research Group Recommended Adaptations
Number of participants	4-6 (research team decision)	4-6
Number of facilitators	2	2
Number of sessions	14	14
Session length	45 - 60	45
Session number per week	2 /week (preferably on different days)	Not discussed
Session order	Retained	Altered
Themes	All retained	8 retained (some with alternative wording)
Physical games	Variety of games, adapt to need e.g. skittles, chair exercises. Do a risk assessment	(Session 1) Variety of games including boules and skittles (Session 3 “Bingo”) Exercise bingo using pictures instead of numbers with chair based exercises
Sounds	Play a sound to match to 1 of 3 pictures. Be aware of sensory sensitivities	(Session 8 “Sounds”) Sound clips played to match with music artist. Or discuss sounds of different settings e.g. beach (Session 4 “Music”) Match sound of instrument to photo. Opportunity to play instruments (as in original manual)
Childhood	Discuss pictures or objects brought in by group. Use visual prompts to discuss life e.g. picture of beach or caravan to discuss favourite holiday. Or my life board game. Be mindful of child trauma	Not included
Food	Have food to taste/smell/touch or food boxes/realistic pretend food. Discussion around preferences. Categorising foods to different meals. Check for swallowing or sensory issues.	(Session 2) Variety of food items – discussion around preferences, categorising to different mealtimes
Current Affairs	Use easy read news with topics of interest or updates related to TV programmes, popular YouTube/TikTok videos of interest. Or discuss a public figure or character from TV.	(Session 4 “Routines”) Use visual resources to consider routines and discuss healthy routines/sleep.
Faces and Scenes	Pictures of scenes and celebrities one at a time and discuss preferences	(Session 7) Photographs of celebrities and places, discuss preferences
Word Association	Match pictures or objects together e.g. famous celebrity pairs. Or finish the song. Discuss associations rather than right/wrong.	(Session 11) Link famous celebrity pairs or sportsperson with sport
Being Creative	As in original manual or discuss creative interests	(Session 6 “Craft”) Planting seeds (as in original manual) or decorating cakes. Offer sensory experience.
Categorising Objects	Use picture to indicate categories and small number of pictures/objects at a time. Could make a collage. Odd one out with 4 pictures	(Session 5 “Categories”) Use objects and photos to categorise items by colour, size, species
Orientation	Use pictures to discuss local area of present or past, discuss time of year and festivals or places people have been to.	Not included

Money	Pretend/pictures of money, discuss preferences of what to buy, what costs more. Or have a ‘shop’ that group members can buy things from with pretend money.	Not included
Number Games	From original manual but with large versions of dominoes, cards, bingo or snakes and ladders.	Not included
Word Games	Story cube game. I went to the market game	(Session 12 “Cognitive Games”) Tactile sensory naming game to identify hidden object by touch
Team Quiz	Visual or sound quiz or play games enjoyed from previous sessions and/or have a party with music and food.	(Session 9 “Quiz”) True/false quiz to facilitate discussion rather than right/wrong
Additional themes and activities:	Not applicable	(Session 13 “Film”) Quiz on popular films, pairing activity with films or discussion (Session 14 “Holidays”) Multi-sensory use of touch, taste and sound to evoke memories
Feedback form	Keep but simplified language (research team decision)	Not discussed
Input from carers	Carers can attend the sessions if needed but do not have to Give carers information about the group	Add information to educate carers on CST and the benefits of it by creating an additional resource for carers and giving a short intro to carers during session 1
More general adaptations		Develop a resource to make CST part of daily life – created additional CST activity workbook with 14 short activities.

Results From Phase 4: CSTIDD Feedback

Following recruitment and randomisation, four participants with intellectual disability and dementia were allocated to the pilot CSTIDD group. Two withdrew prior to the group starting, one due to mobility difficulties and another due to challenges committing to it.

Two participants attended the group, one male participant age 62 attended 12 of 13 sessions, one female participant age 54 attended four sessions, both with Down's Syndrome. The final session was cancelled due to adverse weather and could not be rescheduled so there were only 13 sessions. The cancellation of the final session meant the interview also planned for that session could not take place so there was an unplanned delay between the final session and interview. In discussion with carers, the female participant did not take part in the interview due to this as the carer felt they did not recall the group and would be unable to participate. Therefore, one group participant (male) took part in an interview.

The paid carer of the female participant did not respond to requests to interview, and the paid carer of the male participant declined to take part. One female family carer of the male participant took part in an interview one month after the group finished.

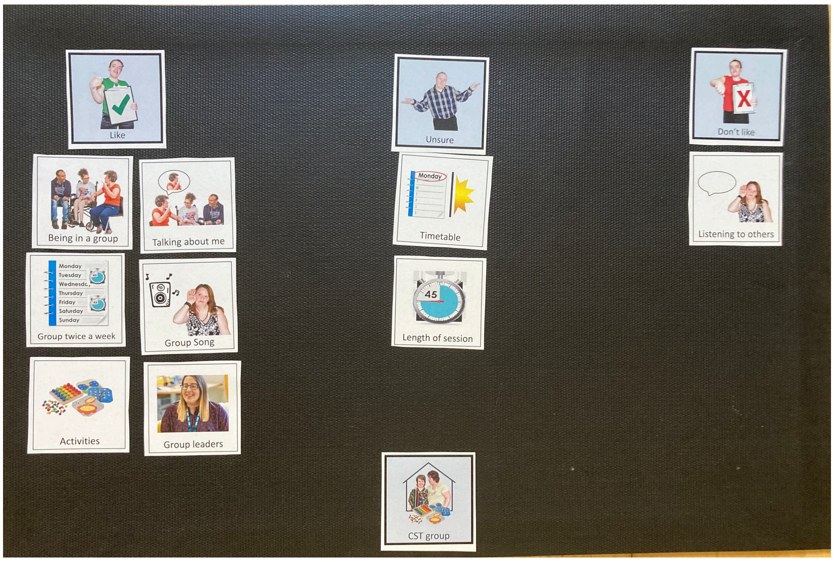
There were two main group facilitators (one occupational therapist and one psychologist) from community intellectual disability teams trained in CST. Both facilitated the sessions however if one was unable to attend, a third professional from a community intellectual disability team untrained in CST attended so there were always two staff members present. Both main group facilitators consented to take part in interviews.

Qualitative Analysis Findings of the Internal Pilot Group

Due to the time delay between the final session and interview, the author decided not to ask for feedback about specific activities but keep to more general aspects of the group. Aspects of the CSTIDD group were recalled though it was unclear at times whether the participant was responding about groups in general or specifically about the CSTIDD group. An image of the Talking Mat created from the interview with the group participant is presented in figure 2. The participant often named the images on the cards and sometimes gave additional comments which is incorporated in the findings below, but did not elaborate on all the items.

Figure 2

Talking Mat From the Interview With the Group Participant



Overall Impression of CSTIDD

In line with findings from phase 1, the CSTIDD group was enjoyable for the participants; they “really enjoyed (the group) and they engaged well with it” (Facilitator 1), they were “excited” to attend, “motivated” and discussed it with carers after the group: “when he comes back he's always telling the staff what he's done, who he's seen, and what they've done when he got there. So yes, he does enjoy very much what he's done” (Carer). Both facilitators also enjoyed running the group and seeing the participants benefit from it: “running a group is a lovely thing and you get a lot back from it, don't you? And they get a lot from it” (Facilitator 2).

The facilitators and carer felt the attendees “got a lot” from the groups. Facilitators found that talking about interests “trigger[ed] some memories” (Facilitator 1) that they then enjoyed discussing. One participant would “remember or recall a kind of funny thing that happened in previous sessions or funny joke that someone said and that was nice to see”.

(Facilitator 1). Carers had told facilitators that they had seen “a bit of improvement or not deterioration anyway.” (Facilitator 2).

The participant liked being in a group compared to being in a one-to-one setting: “I like to do that [being in a group]” (Participant), the carer and facilitators also highlighted the positive social aspects of the group and “chatting to other people not just the one to one” (Carer). Routine was also highlighted as a helpful aspect: “I think he really liked knowing who was going to be there and what he was going to do, knowing that every Wednesday or every twice a week, he'd go and see one of us” (Facilitator 1).

The carer also felt that the groups were important because “it gets him out of the house” compared to at home where he “gets bored and he basically goes and lays down in bed and goes to sleep” (Carer). The carer also appreciated that it was a specifically for dementia and intellectual disabilities as “he's got two kinds of problems” and it can be “difficult for him to go a dementia group because everybody's different” (Carer). The facilitators and carer expressed a wish and/or plans for the group to run again as it was something they viewed as enjoyable and beneficial for the participants: “if they run the group again I’d be more than keen for [the participant] to attend” (Carer).

Impression of the CSTIDD Activities

In line with the findings from phase 1 and 2, the activities were viewed positively, with physical games, sounds, childhood, food, current affairs, faces and scenes, word association, being creative, orientation, money and number games specifically mentioned as going well or enjoyable for the participants: “when he was talking about his childhood you could really see the passion and excitement” (Facilitator 1), “They really liked the number games, dominos and bingo and snakes and ladders.” (Facilitator 2). The participant talked in a particularly positive way about his interest in music and the group song, and dominos which is a game he plays regularly “I play dominoes with [my keyworker]. I do yeah and I beat her [laughing]” (Participant).

The categorising objects session was more challenging; participants were able to discriminate between food and cars but then got “a bit mixed up…I think that’s because she was tired” (Facilitator 2). Facilitators also found the word games session challenging as participants “couldn't read”. They did not think participants would be able to do the story cube and found ‘I went to the market’ “too tricky as well”. However they made use of the variety of activities enhanced by phase 3 as they “did do the further adaptation…’what's in the box’. And so that went down really well.” (Facilitator 2). Unfortunately, the final session was cancelled due to adverse weather and was seen as important for a sense of ending; “I know the participant [who attended most of the sessions] was a bit upset that we weren't able to do our final sessions and kind of have that form of ending” (Facilitator 1), highlighting the importance of retaining the ending session confirmed in phase 3.

Facilitators found that participants enjoyed the physical and tactile parts to the activities: “something that they could feel and touch, and so we had all the fake money” (Facilitator 2) which was in line with findings from phases 2 and 3 to increase the sensory aspects. For the being creative session they used “air dry clay so it's much more tactile and they can really do whatever they want to do with it and it’s sensory” (Facilitator 2), and for the money session, the “little shop where they could buy things like it says in [the CSTIDD supplement] went down really well” (Facilitator 2).

Impression of the CSTIDD Supplement to the Manual

Facilitators found the CSTIDD supplement “comprehensive”, “easy to follow” and “a really nice foundation and template, to build on” (Facilitator 1). They found it helpful to have both the original CST manual and the CSTIDD supplement; “it's definitely good to have both of them…we had both of them open and…we did some of the some of the activities from the main one and some from the adapted one” (Facilitator 2). However the facilitators found that preparing the materials took more time than they expected as they had to edit the resources or source them. For example getting the pictures in the supplement “onto a page so they're big enough but some of them were blurry, and then printing out and laminating it… it took a lot of time” (Facilitator 2). Also, “there were a couple of times where we [needed to] create our own resources” (Facilitator 1) to “simplify” them or find resources/images to match the interests of the group: “it wasn't really changing the activity…we didn't feel that the participants would get or would relate to it. So we just made it a bit more accessible for them" (Facilitator 1).

Although feedback forms at the end of sessions were completed, facilitators felt they did not gather very reliable data as clients sometimes answered "an enthusiastic yes for enjoying the session and then a similar yes for what they didn't like" (Facilitator 2). Both facilitators felt that a Talking Mat "is a useful idea" (Facilitator 2) for gathering feedback.

Practical Considerations of Running CSTIDD

As highlighted in phases 2 and 3, some carer involvement was helpful. One participant attended alone and one participant attended with a carer which facilitators thought worked ok; "[one] carer stayed in the group, but she was more active, so she would support the participant in reminding her about certain things or just breaking down questions" (Facilitator 1). The participant who attended alone occasionally needed support with using the toilet and the carers "forgot to come and pick him up sometimes" so facilitators suggested it could be helpful for carers to be nearby "perhaps it's helpful for the carers to hang around in the building" (Facilitator 2).

Some practical considerations to running the group which did not come up in phases 1-3 included that "it would be better to do [the group] in the mornings" (Facilitator 1) to avoid tiredness and at a time of year "avoiding the extreme weathers because that might it's likely to have an impact on participant participation" (Facilitator 1). Location of the venue was important: "if there was somewhere held locally I think that would be more doable." (Carer) as well as practical aspects like being able to park: "it took me almost an hour to drive to get to the location… parking wasn't great… that could have been another contributor that deterred people from coming…the one who was consistent, he just walked" (Facilitator 1). The group was also unable to have "tea, coffee, refreshments…because basically at that facility we weren't able to bring in that stuff" (Facilitator 2) which they wanted to change when running again.

All interviewees felt that twice weekly sessions worked and both facilitators felt that two in one day would be too much: "I don't think having two a week was a problem. I think it was nice. I personally I think it worked better than having two in a day…I think that would have been too much” (Facilitator 1) agreeing with the findings from phases 2-3. However as mentioned in phase 2 findings, timing with participants’ other activities was a challenge: “it was right after her swimming, so she went swimming and then had to come straight [to the group]. So the times when she did come, she literally fell asleep” (Facilitator 2).

Facilitators also commented on delayed diagnosis impacting recruitment to the group; “by the time people with learning disability have got a diagnosis that's sort of a bit too far gone to really benefit from the group” (Facilitator 2) and subsequently, ability to engage in the group: “she was on the borderline really of benefiting from the group. She did…but we had to adapt it more for her, for her to really get the benefit of it” (Facilitator 2).

Finalised Adapted Intervention: CSTIDD

Following these four phases, the CSTIDD supplement to the CST manual was finalised (see Appendix S). The 14 original themes were kept but adaptations and alternative activities suggested to fit the population. Adaptations included the use visual aids and easy read as well as including images and visual prompts in the supplement for facilitators to use if appropriate. A range of alternative activities were suggested for each session to cover the need to tailor to ability and interest. Guidance was included about the importance of knowing information about past trauma, sensory sensitivities or risk beforehand. The importance of carrying out a risk assessment for physical activities and having food in the sessions was also included in specific sessions and in a food risk assessment sheet.

There were some issues raised in phase 4 around the practicalities of running a group which were added to an introductory section of the supplement. The option for carers to either stay in the group or not depending on need was also included here given that findings in phases 1, 2 and 4 discussed that carers could stay and this is not discussed in the main manual. Findings suggested that it would be appropriate to follow the main CST guidelines in terms of session length, frequency and number of facilitators which was also included in this section.

Facilitators felt the feedback questions asked in CST, which were slightly simplified for the pilot of CSTIDD, gathered limited data. Suggestions to use a Talking Mat or more visual methods to gather feedback were added to the supplement with example images to facilitate this.

Discussion

This study adopted a qualitative approach to adapt CST for people with intellectual disabilities, similar to other published adaptation studies of CST (Perkins et al., 2022). This adaption builds on the increasing number of therapeutic interventions for people with intellectual disabilities and dementia (MacDonald & Summers, 2020). As in previous research (Acton et al., 2022; Ali et al., 2022; Jervis et al., 2021), findings showed that CST required some modifications to be used with people with intellectual disabilities and dementia. A key findings was that it needed to be able to be tailored to ability and interest given the heterogeneity of the population which is in line with advice from the BPS that interventions should be adapted to an individual’s disability and health, social circumstances (The British Psychological Society, 2015).

Another key finding was the need to be aware of additional needs of the population, such as awareness of past trauma, sensory sensitivities or risks related to physical activities or food given dysphagia being a key concern in the intellectual disability population (Robertson et al., 2017). These additional needs are particularly relevant to the intellectual disability population however could also be relevant to those without intellectual disability as has been noted by the Camden and Islington Memory Services who applied a trauma informed approach to CST (C&I QI Hub, 2023). The literature review identified that people with intellectual disabilities and dementia may not have an understanding of dementia. This did not come up as something to consider during the adaptation process. Perhaps this is because this is outside the remit of CST which does not include psychoeducation but is rather focused on cognitive stimulation. However it could nevertheless be helpful for group facilitators to be aware of the varying understandings of dementia within the group.

Findings from the pilot of CSTIDD highlighted positive feedback from all perspectives. Although no claims about feasibility and acceptability can be made at this stage due to the small sample size. Given the small sample size it will be important to further explore whether the intervention is adapted sufficiently in the feasibility RCT, of which this is a part (Ali et al., 2023). This will be an invaluable step towards an evidence-based non-pharmacological intervention for people with intellectual disabilities and dementia.

Strengths and Limitations

There are a number of strengths of this study. Firstly, following ADAPT enhanced the rigour of the adaption (Moore et al., 2021). The ADAPT framework was followed in a number of ways including the transparency and detail of the adaptation process itself, not just the piloting of it which has been the case in previous research adapting interventions for this population group including CST (Bevins et al., 2015; Crook et al., 2016; Jervis et al., 2021; Kiddle et al., 2016; Ward & Parkes, 2017). Maintaining the integrity of the intervention and the inclusion of a diverse range of stakeholders at each stage of the process was also a key strength in line with ADAPT.

Another strength was the involvement of PPI in the research, and seeking to include the views of people with intellectual disabilities and dementia through the use of Talking Mats, rather than solely seeking the views of professionals or carers which is often the case (Bevins et al., 2015; Ward & Parkes, 2017). Talking Mats have been used successfully with people with dementia (Murphy, 2014; Murphy et al., 2010) and people with intellectual disabilities (Murphy & Cameron, 2008). However this is the first time Talking Mats have been used in research with people with both intellectual disabilities and dementia. This is a promising method that can be used to include individuals with intellectual disabilities and dementia in research. It should be held in mind that the unplanned delay between groups and interview might have impacted the validity of the data. However, the promising engagement in the method warrants further testing in more participants which will take place in the feasibility RCT.

Being able to only interview one group participant and their carer in phase 4 was a limitation. Given the heterogenous nature of the people group, there may be other adaptations needed that were not picked up by this pilot due to the small number of participants. The small number of available interviewees in phase 4 also meant there was too little data to carry out thematic analysis which reduced the rigor of the methods. These limitations will be addressed by the feasibility RCT in which more CSTIDD groups and interviews will be taking place.

Substantial issues around recruitment to the CSTIDD pilot was a major obstacle in the number available for interview. Barriers to recruitment appeared to include delays in diagnosing dementia leading to a small pool of participants and decline in the cognition to the point where participants would have no longer been able to participate in the group. Other research has included those with possible dementia without a diagnosis (Jervis et al., 2021; Kiddle et al., 2016; Ward & Parkes, 2017) and in clinical settings CSTIDD could be offered to those without a dementia diagnosis in line with advice from the BPS that the long diagnostic process should not preclude access to interventions (The British Psychological Society, 2015). However for the purposes of this research, it was not possible to include those without a dementia diagnosis as otherwise as it would hinder the ability to examine the feasibility of CSTIDD specifically for people with intellectual disabilities and dementia. Location of the group, and subsequent reliance on transport, physical co-morbidities, lack of available carer to support attendance and busy timetables also contributed to the low group numbers.

Only being able to interview at the end of the group and the gap between the group and interviews, due to the session cancellation and delays with ethics amendments, might have compromised the quality of the data and meant that useful feedback on each activity might have been missed. Another study found a similar difficulty with participants being unable to attend the final group and that delaying interviews (Bevins et al., 2015). This has informed the interview procedures for the feasibility RCT to reduce the chance of this happening.

A benefit and a challenge of this study was that new literature was identified through the course of the research. This brought challenges of needing to adapt and respond to this. However, it was also beneficial to collaborate and share ideas and knowledge.

Implications

Now that there is a standardised adaptation of CSTIDD, further research is needed to address step 3 of ADAPT and evaluate this adapted intervention. The feasibility RCT that this study sits within will be a very important step in exploring the acceptability and feasibility of CSTIDD as an adapted intervention. This will be the most comprehensive piece of research to date about CST in this population and will inform whether a larger RCT could take place to explore outcomes more fully.

Future research would benefit from extended recruitment timescales to account for potential recruitment delays in this population. The BPS recommends that diagnosis should not limit access to interventions for people with intellectual disabilities and possible dementia (The British Psychological Society, 2015), however interventions cannot be developed and tested rigorously without testing them with those who have a specific diagnosis. Delays in diagnosis are impacting research and therefore the development of evidence-based interventions. Perhaps this is why it seems that clinical practice is therefore needing to move ahead of research. Placing an emphasis on the improvement of diagnosis of dementia in people with intellectual disabilities may improve the ability to recruit to research and therefore improve the development of appropriate interventions for this population.

Previous research (Watchman et al., 2018) and part 1 of this thesis identified that research should more readily hear the perspectives of people with intellectual disabilities and dementia. This study has demonstrated the effective use of Talking Mats to facilitate this. This approach could be used in future research to hear the perspectives of this population more readily.

Conclusions

This paper describes the adaptation of CST for people with intellectual disabilities and dementia, with the support of a diverse range of stakeholders and through an initial pilot group. A CSTIDD supplement has been created which will be used in a feasibility RCT to test the acceptability and feasibility of the intervention. It is a promising new intervention for this population.

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Part 3: Critical Appraisal

Introduction

In this critical appraisal I outline some reflections about my experience of carrying out research in the field of intellectual disabilities and dementia. I start by locating myself and my experiences, which led to my interest in this area of research and contributed to the process of it. I will then discuss some of the challenges in general, my emotional response to the research process, and some reflections on the process of adapting Cognitive Stimulation Therapy (CST) for this population. Lastly, I will give some reflections on the learning that I have taken from this process. This critical appraisal is informed by a reflexive research journal that was kept throughout the research process.

Location of Myself in the Research

The acknowledgment that the researcher and their context, experiences and assumptions impact the qualitative research being conducted is an accepted premise of qualitative research (Finlay, 2002). Reflexivity is consequentially an important, if not essential part of qualitative research to increase awareness of potential researcher biases that might impact the research, deepen knowledge and identify potential complicity in systems of oppression (Dodgson, 2019; Finlay, 2002; Mitchell et al., 2018).

I was aware from the outset of this research as an able bodied, cognitively able, woman in her 30's that I was in an 'outsider position' when it came to researching views and experiences of people with intellectual disabilities and dementia. I had witnessed the experiences of people with dementia and their carers while working in a professional capacity and from a personal perspective when my grandmother was diagnosed with dementia. I had also witnessed experiences of people with intellectual disabilities at a day service. However, I do not have either dementia or intellectual disabilities and this 'outsider position' meant that it was particularly important for me to reflect on issues of power and seek to use participatory research methods to try and minimize these power differentials (Dodgson, 2019).

My selection of this project was influenced by a motivation to give a voice to those who may have less of a voice, whether that be due to issues related to power or ability. This motivation is born out of my personal experiences of faith and family in which it is highly valued to “Speak up for those who cannot speak for themselves” (The Holy Bible, New International Version®, 2011, Proverbs 31:8), as well as my experience of being a mum to two young children whose communication abilities are still developing, and through several years of professional experience working with older adults with dementia, whose voices were not always heard. From these experiences, I held the belief that one does not require verbal ability to have a voice, as desires and wishes can be expressed in a number of ways including behaviour (Cohen-Mansfield, 2000; Cohen-Mansfield & Werner, 1995). It is therefore possible that a bias was present in this research where I was motivated to identify this in the data.

In order to minimise the possible risk of bias and my own experiences and assumptions impacting the research, I made regular use of my reflexive research journal and tried to not make assumptions but maintain a curious stance while collecting and analysing data.

Dealing With Changing Plans and Expectations

There were a number of changes of plans in the course of this piece of research. The first project I started fell through which led to me starting this project a year later, half way through my second year. There have also been other difficulties with this piece of research including delays with ethics amendments and recruitment challenges, so there have been many changes in expectations, plans and challenges over these few years. Many times I have felt confused, unsure where to start and wondering whether I would complete the research project. When you read a paper in a journal it is written as if it all went to plan and you do not see the back story behind it. I have wondered whether all research happens like this, with so many delays, setbacks and changes in plan. I wondered whether the challenges experienced in my project happen in other research with people with intellectual disabilities and dementia, and whether this is a contributing factor to the relatively small amount of research in this field.

Reflections on the Systematic Review

Managing Emotional Responses

When reading the papers in the systematic review, there were some that contained experiences of neglect of people with intellectual disabilities and dementia. I had not fully anticipated the emotional aspect of this side of the research or the experience of reading in the library with tears rolling down my cheeks. The sadness led at times to anger that there might be many more people sitting in homes around the country with their needs not being addressed. The responses and reflections of the researchers showed me that I was not alone my emotional responses to neglectful situations. That, along with the more positive experiences described in other studies also brought hope that this is not the sole experience of people with intellectual disabilities and dementia.

During the systematic review, I also experienced a dilemma when considering the role of carers. I held a prior view that carers are kind, sacrificial, and often do not receive adequate verbal or monetary appreciation for their role. This contrasted with some examples in studies of how neglectful experiences seemed to relate to carers having a lack of understanding and knowledge. I felt conflicted in considering how to articulate this; in not wanting to articulate blame and overburden carers but also wanting to highlight the impact on individuals with intellectual disabilities and dementia. I found that moving to a ‘both-and’ rather than an “either-or” stance (Andersen, 1992) helped to navigate this dilemma. That both individuals with intellectual disabilities with dementia as well as carers can be valued, and that cares can be kind and sacrificial and also sometimes need further knowledge.

I also found myself considering deeper questions around ageing and what it means to be human, which I had not expected when I set out on this research. I sometimes found my emotional responses to be a distraction when trying to code the data in the reviews and made it challenging to hold a curious stance, however I found the reflexive journal a helpful tool in noting these experiences and then trying to return to the curious stance in these moments in particular.

Reflections on the Empirical Paper

Working With the Wider Research Team

I felt like I learnt a lot from carrying out the empirical research. It was my first experience of working on a funded research trial and many times I felt out of my depth with new jargon, processes and structures to learn. I played a key role in writing-up the project protocol publication (Ali et al., 2023) and found it useful hearing the views and input from different members of the research team. At the same time, with multiple voices in the mix, all working in different locations, it was sometimes difficult to come to a consensus on topics of discussion. Although a key part of the research team, I sometimes felt removed and on the edge, unsure of what was happening with information not always being passed along, for example information about groups starting, or delays with ethics amendments. This was a challenge which I had to address by sending follow up emails and discussions with my supervisors.

Recruitment and CSTIDD Group Challenges

Another challenge was recruitment to the Cognitive Stimulation Therapy for intellectual disabilities and dementia (CSTIDD) trial. This meant that rather than having access to participants from multiple groups, only one pilot group took place within the window of time available in the clinical psychology doctorate. Furthermore, the pilot group had only a small number of participants.

There were a number of contributing factors to the recruitment difficulties. Firstly, the pool of potential participants was relatively small, this was also compounded by delays in people with intellectual disabilities being given a diagnosis of dementia. The issues with diagnosis seemed in part due to difficulties diagnosing dementia in this population (Janicki, 2022; Wissing et al., 2022) the faster progression of dementia in people with intellectual disabilities and dementia (Kerr, 1997) as well as procedural and staffing issues in local teams leading to long wait lists of people waiting for dementia assessments, but relatively few having them. Due to the long wait list, sometimes by the time potential participants received a diagnosis, the dementia was too advanced to be able to take part.

Adverse weather affected the running of the group with a heatwave delaying the start and snow cancelling the final session. Group participants contracting COVID-19 also delayed the start of the group. With the participants being a vulnerable population, changes to the running of the group due to these factors was needed to ensure their wellbeing. However these delays also impacted participants' cognition and ability to participate in the trial, CSTIDD group and participants ability to take part in the post group interview which was disappointing.

At one point it was discussed whether to change the trial protocol to include those with suspected dementia who were waiting for a diagnostic assessment, as has been done previously (Jervis et al., 2021). This would have increased the number of potential participants for the trial and open up the groups to people awaiting a diagnosis (The British Psychological Society, 2015). However, it was felt that this would limit the data and the ability to apply the findings specifically to people with a diagnosis of dementia, so the inclusion criteria of a confirmed dementia diagnosis was kept. CSTIDD facilitators discussed these recruitment and diagnostic challenges in interviews and said that when they run the group again outside of the trial that they will accept those without a diagnosis to minimise these difficulties in clinical practice.

The above mentioned delays also had a knock on impact on facilitators. Some trained facilitators moved to another team prior to the pilot group starting, therefore more facilitators needed to be found and trained. All of this pushed the timescale of the project back significantly and therefore impacted on my ability to carry out more interviews from group participants, carers and facilitators.

For a number of months I was hoping that another group would run, but each month it would be pushed back. I found this uncertainty challenging; sometimes experiencing a sense of relief to not yet have another task on my already overrun to do list, yet more often experiencing underlying anxiety rumbling on. I wondered if my experiences might mirror experiences in the wider system, with people with intellectual disabilities and their carers waiting on a waiting list for a meeting to discuss a potential diagnosis. I wondered if they might they also experience the dichotomy of both relief and anxiety to not yet have a dementia assessment.

Working With Experts by Experience

I had hoped that the empirical research would be inclusive. This came from noticing that I was researching from the outsider position, my values, as well as from the systematic review which identified how little research there has been that has sought the views and experiences of people with intellectual disability with dementia. I therefore wanted to include the voices of this population in my research and co-create with experts by experience.

The review highlighted that the main methods of seeking the views of this population was either interviews or with an ethnographic approach. I was aware from the literature that other communication aids such as Talking Mats have been used with other populations with cognitive and communication challenges and wondered if this would be a facilitative aid to seek the views and experiences of the group participants in my empirical paper. I therefore carried out Talking Mat Foundation level training which I found a beneficial and rich experience, which I have also applied to other areas outside of this research.

As a Talking Mat approach had not been used in research previously with people with intellectual disabilities and dementia, I wanted to consult with professionals and people with a lived experience of intellectual disabilities and/or dementia to explore how best to do this. I consulted with professionals who had experience working with people who have intellectual disability and dementia, including an assistant psychologist who had carried out many dementia assessments for people with intellectual disabilities, and a speech and language therapist with experience of working with people with intellectual disability and dementia.

I also discussed the methodology with someone linked with the project who has Down’s Syndrome and good knowledge of dementia. Before I contacted her I felt a little uncertain about how best to go about this; I spent time considering how best to formulate my email and how to articulate the research and my questions in an accessible, but also not infantilising way. When we spoke, we had a really interesting conversation and I came away from it appreciating her input into the project and the people that support this to make it happen.

Following this, I tried a few avenues to invite others with lived experience of intellectual disabilities and/or dementia to participate in a focus group about the methodology. I explored this through an intellectual disability charity linked with the project, through a researcher with experience of coproduction with people with intellectual disability and through a national steering group for people with intellectual disabilities and dementia. I had budget to offer payment to those who would take part and created easy read information about the project and focus group (see Appendix T), however, no one came forward to take part in the timescale that I had. I found this disappointing, however it was perhaps an ambitious aim given my project timescale was shorter than normal, having started this project half way through my second year rather than in my first year. Starting this earlier on would have allowed more time to build connections and follow up with contacts.

Despite not being able to gain feedback about the Talking Mats method from more people with lived experience of intellectual disability, I was pleased that I persevered with developing it and putting it into practice as it enabled a participant with intellectual disability and dementia to share their perspective. It will also hopefully contribute to many more people being able to share their experiences through the methodology being used in the feasibility RCT and other research.

Conclusion

Undertaking this research has had many challenges however I have also found it interesting, enjoyable and I have learnt a huge amount in the process. I have learnt a lot about the many different processes needed to undertake research and to adapt an intervention. I have learnt about the importance and challenges of including experts by experience in the research process. I have also learnt a lot in the process about the views and experiences of people with intellectual disabilities and dementia. It has sparked many other thoughts and discussions that I had not anticipated. It has felt like a privilege to be part of amplifying these voices in order to improve research and practice in this field.

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Appendices

Appendix A

Search Strategies

Below is the search strategy for PsycINFO and Medline and following this is the search strategy for the Web of Science.

1. exp Intellectual Development Disorder/
2. (Intellectual Disabilit* or Learning Disabilit* or Down? Syndrome or Learning Difficult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
3. 1 or 2
4. exp Dementia/
5. (Dementia or Alzheimer* or Major Cognitive Disorder or Memory).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
6. 4 or 5
7. exp Client Participation/
8. exp Client Attitudes/
9. (Opinion* or View* or Perspective* or Attitude* or Experience* or Voice* or Perception* or Participation or Involve* or Engage* or Input or Contribut*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
10. 7 or 8 or 9
11. exp Qualitative Methods/
12. exp Interviews/
13. (Qualitative* or interview* or focus group or participatory action research or photovoice or talking mat* or easy?read or Co?production or case study).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

14. 11 or 12 or 13

15. 3 and 6 and 10 and 14

Below is the search strategy for the Web of Science:

(((ALL=(“Intellectual Disabilit*” OR “Learning Disabilit*” OR “Down*Syndrome” OR “Learning Difficult*”)) AND ALL=(Dementia OR Alzheimer* OR “Major Cognitive Disorder” OR Memory)) AND ALL=(Opinion* or View* or Perspective* or Attitude* or Experience* or Voice* or Perception* or Participation or Involve* or Engage* or Input or Contribut* or Co*production)) AND ALL=(Qualitative* or interview* or focus group or “participatory action research” or photovoice or “talking mat*” or “easy*read” or “case study”)

Appendix B

Statement of Contributions From Others Involved in the Project

Joanna Carter (JC) and Cheryl Francis (CF) are both involved with this project. CF is a trainee in the year below and currently still completing the project. The project was also part of a funded feasibility RCT with other researchers involved in this work. The contributions are summarised below.

Task	Contributor
Literature Review Search and Analysis	JC
Independent application of eligibility criteria and quality checklist	Amelia McFeeters (Honorary Research Assistant)
Design of the empirical paper (the qualitative aspects of the wider project)	JC under the supervision of Dr Georgina Charlesworth (supervisor) and Professor Aimee Spector (supervisor and co-principal investigator)
Ethics Application and amendments	The original ethics application was submitted by Aimee Spector JC took a lead on the substantial ethics amendments related to the qualitative side of the project: creating and updating relevant information sheets, consent forms and interview schedules. Updating the protocol and amendments tracker with aspects related to the qualitative side of the project. The non-qualitative aspects of the project were managed and facilitated by Professor Aimee Spector (Supervisor and co-principal investigator), Afia Ali (co-principal investigator), Sarah Hoare (Research Assistant), Anna Cattrell (Research Delivery Manager), Liberty Newlove (Senior Research Assistant).
Analysis of iCST data (phase 1)	JC
Facilitating focus groups and interviews (phase 2)	Afia Ali and Sarah Hoare
Transcribing and analysing data from focus groups and interviews (phase 2)	JC
Discussions with CWRG (phase 3)	Afia Ali and Sarah Hoare
Analysis of similarities and differences between phase 1 & 2 and CWRG (phase 3)	JC
Creation of the supplement	JC and Sarah Hoare
Development of the interview methodology including consultation with stakeholders	JC
Recruitment of group participants, carers and facilitators to interviews	JC
Semi-structured interviews with group participants, carers and facilitators	JC interviewed 1 facilitator, 1 carer and 1 group participant CF interviewed 1 facilitator
Transcription of interviews and data analysis	JC

Appendix C

Ethical Approval Confirmation for CSTIDD Feasibility RCT

Health Research Authority

East of England - Essex Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

28 January 2022

Professor Aimee Spector
Senior lecturer-Professor of Old Age Clinical Psychology
University College London
1-9 Torrington Place
London
WC1E 7HB

Dear Professor Spector

Study title:	**Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.**
REC reference:	**21/EE/0247**
IRAS project ID:	**306756**

Thank you for your letter of 27 January 2022, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Relevance of the research to the impairing condition

The Committee agreed the research was connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

The Committee agreed the research could not be carried out as effectively if it was confined to participants able to give consent.

Arrangements for appointing consultees

The Committee considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 135 of the Mental Capacity Act (Northern Ireland) 2016) to advise on whether participants lacking capacity should take part and on what their wishes and feelings would have likely to have been if they had capacity.

The Committee was satisfied with the arrangements to identify and appoint consultees.

Balance between benefit and risk, burden and intrusion

The Committee agreed that the research has the potential to benefit participants lacking capacity without imposing a disproportionate burden on them.

Additional safeguards

The Committee was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 137 of the Mental Capacity Act (Northern Ireland) 2016).

Information for consultees

The Committee considered that the information to be provided to consultees about the proposed research was adequate.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants

4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
GP/consultant information sheets or letters [GP Participation letter]	2	07 September 2021
IRAS Application Form [IRAS_Form_28092021]		28 September 2021
Letter from funder [Letter from Funder]		24 November 2020
Non-validated questionnaire [Participant Demographic data form]	1	08 December 2021
Non-validated questionnaire [Carer interview demographic data form]	1	08 December 2021
Other [Personal Consultee Declaration form TC]	2.1	20 December 2021
Other [Personal Consultee Declaration form clean]	2.1	20 December 2021
Participant consent form [Carer interview consent form]	1	08 December 2021
Participant consent form [Service user consent form feas study clean]	2.1	15 December 2021
Participant consent form [Service Users consent form feas. study tracked changes tracked]	2.1	15 December 2021
Participant information sheet (PIS) [Carer interview information sheet]	1	02 December 2021
Participant information sheet (PIS) [Participant information sheet TC]	3	21 January 2022
Participant information sheet (PIS) [Participant information sheet clean]	3	21 January 2022
Participant information sheet (PIS) [Personal Consultee information sheet TC]	3	21 January 2022
Participant information sheet (PIS) [Personal Consultee information sheet Clean]	3	21 January 2022
Participant information sheet (PIS) [Nominated Consultee Information Sheet TC]	2	21 January 2022
Participant information sheet (PIS) [Nominated Consultee information Sheet Clean]	2	21 January 2022
Protocol [protocol TC]	8	15 December 2021
Protocol [Protocol clean]	8	15 December 2021
Summary CV for Chief Investigator (CI) [CI CV]	1	23 September 2021
Validated questionnaire [EQ-5D-5L]		
Validated questionnaire [QoL AD]		
Validated questionnaire [GDS]		
Validated questionnaire [SIB]		
Validated questionnaire [DLD]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 306756   Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Niki Bannister
Chair

Email:Essex.REC@hra.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Ms Fiona Horton

Lead Nation England: approvals@hra.nhs.uk

East of England - Essex Research Ethics Committee

Attendance at Sub-Committee of the REC meeting held in correspondence.

Present:

Name	Profession	Capacity
Dr Niki Bannister (Chair)	Retired Hospital Doctor	Expert
Ms Sarah Starr	Senior Nurse	Expert
Dr Nkiruka Umaru	Pharmacist	Expert
Dr Andy Stevens	Media Consultant & Retired Principal Lecturer	Lay
Mr Michael Tydeman	Retired Consultant in Drug Development	Lay
Mrs Janice Allen	Retired Assistant Head of Governance Services	Lay Plus
Miss Suzanne Cross	Retired Deputy Corporate Secretary	Lay Plus
Dr Gerry Kamstra	Retired Solicitor	Lay Plus
Dr Katharine Nelson	Veterinary Surgeon	Lay Plus

Also in Attendance

Name	Position (or reason for attending)
Kathryn Davies	Approvals Specialist
Vic Strutt	Approvals Officer
Ms Tracy Hamrang	Approvals Administrator
Miss Aoife Harrington	Approvals Administrator

Appendix D

HRA Approval for CSTIDD Feasibility RCT

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Professor Aimee Spector
Senior lecturer-Professor of Old Age Clinical
Psychology
University College London
1-9 Torrington Place
London
WC1E 7HB

Email: approvals@hra.nhs.uk

07 February 2022

Dear Professor Spector

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.**
IRAS project ID:	**306756**
REC reference:	**21/EE/0247**
Sponsor	**North East London Foundation Trust**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix E

CSTIDD Group Participant Information Sheet

[PLEASE INSERT TRUST LOGO HERE]

PARTICIPANT INFORMATION SHEET FOR SERVICE USERS

A trial of group cognitive stimulation therapy in people with learning disabilities who have memory problems

[Insert your picture here]	My name is **[insert your name here]**
	I am a researcher.
	I am writing to ask if you want to help me.

To help you understand this letter you can:

- Ask someone to read it for you.

- Talk to your carer about it.

- You can ask me a question.

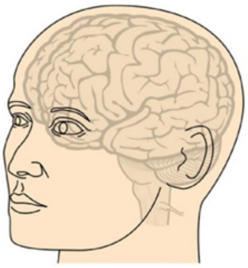
What is my work about?

I want to find out if group Cognitive Stimulation Therapy (CST), helps people with learning disabilities who have memory problems.

Having memory problems means sometimes not remembering where you put things or the names of people.

It means you can’t do some things you used to do and need more help.

In CST we play games and puzzles to help us think.



I want to find out if playing these games can help slow down memory loss.

[PLEASE INSERT TRUST LOGO HERE]

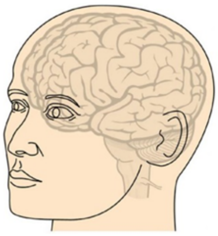
What is my work about?

I want to find out if group Cognitive Stimulation Therapy (CST), helps people with learning disabilities who have memory problems.

Having memory problems means sometimes not remembering where you put things or the names of people.

It means you can’t do some things you used to do and need more help.

In CST we play games and puzzles to help us think.



I want to find out if playing these games can help slow down memory loss.

What will happen to me if I take part?

You do not have to take part.

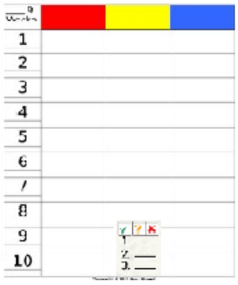
It is up to you.

If you say yes to taking part:

- I will ask your carer some questions about you.

- I will ask you some questions to test your memory.

	You will be put in one of two groups.
	You will not choose which group you will be in. That will be decided by chance like a lucky dip.
	Half the people who take part will be in the CST group.
	The other half will carry on with the things they usually do (usual care group).
	If you are in the CST group, you will join a group of up to 6 people and you will play puzzles and games.

	You will do this 2 times a week for 45 minutes.
	You will do this for 7 weeks
	After 8 or 9 weeks we will ask you and your carer some questions.
	These questions will be about: • Your memory.

	• How you get on with day-to-day activities.
	• Your quality of life.
	If you are in a CST group, we may invite you to take part in a short interview. This will be to hear what you like and don't like about the group. This will be recorded. If we use any quotes (things that you say in the interview), we will not use

	your name or personal information so no one will know it is you. The health professionals in the learning disabilities team will get a copy of the manual at the end of the study so that they can run their own group. If you are in the group that did not get the therapy, the health professionals in your learning disability team might let you join a therapy group at the end of the study. But it is possible that you might not get to join a therapy group.
Do you have to take part?	

No, you do not have to take part.

You can tell me **Yes** if you want to take part.

You can tell me **No** if you do not want to take part.

If you say **No,** it will not change the care you get.

If you say **Yes**, I will ask you to sign a consent form.

You can stop taking part at any time.

What information about me will you take?

We will need to use information about you in this research. This information will include your:

- Name
- Age
- Gender
- Ethnicity
- Contact details (address and telephone numbers)
- Diagnosis

- NHS number

We will use this information to do the research or to check your records to make sure that the research is being done properly.

1234

People who do not need to know who you are will not be able to see your name or contact details.

Your data will have an ID number instead.

We will keep all information about you safe and secure.

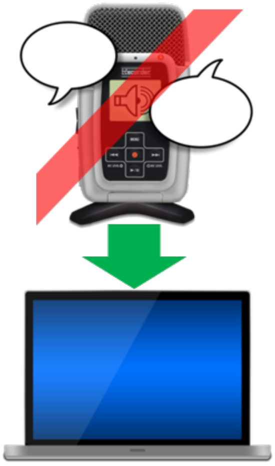
Once we have finished the study, we will keep some of the data so we can check the results.

	We will write our reports in a way that no-one can work out that you took part in the study.

What happens after you have seen me?

 	If you agree to take part in this research: • I will let your GP (doctor) know you are taking part. • The information you give will be private and kept in a locked cupboard for up to year. Then stored away by your local NHS team. • I will not talk to anyone else about you.

This project is funded by the National Institute of Health Research (Award ID: NIHR201934).

	Although what you say to us is not going to be shared, if you say anything to us which puts you or anyone else in danger, we may need to report this to the right person to help.
	The recordings of the groups and any interviews will be put on a computer and deleted from the digital recorder.
	I will not use any information with your name and address when writing any reports, or when any other research

team member needs to look at results.

Where can you find out more about how your information is used?

You can call our research team to ask any questions on…

Local Researcher:
[PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]

Principal Investigator:
[PLEASE INSERT CONTACT DETAILS FOR

	LOCAL RESEARCH TEAM HERE] Or you can call the **Chief Investigators** of the study: Professor Aimee Spector- 0776795925 Dr Afia Ali- 07836 584017 You can find out more information on this website: www.hra.nhs.uk/information-about-patients/
If you want to talk to me	
	You can call me if you have any questions about the study.

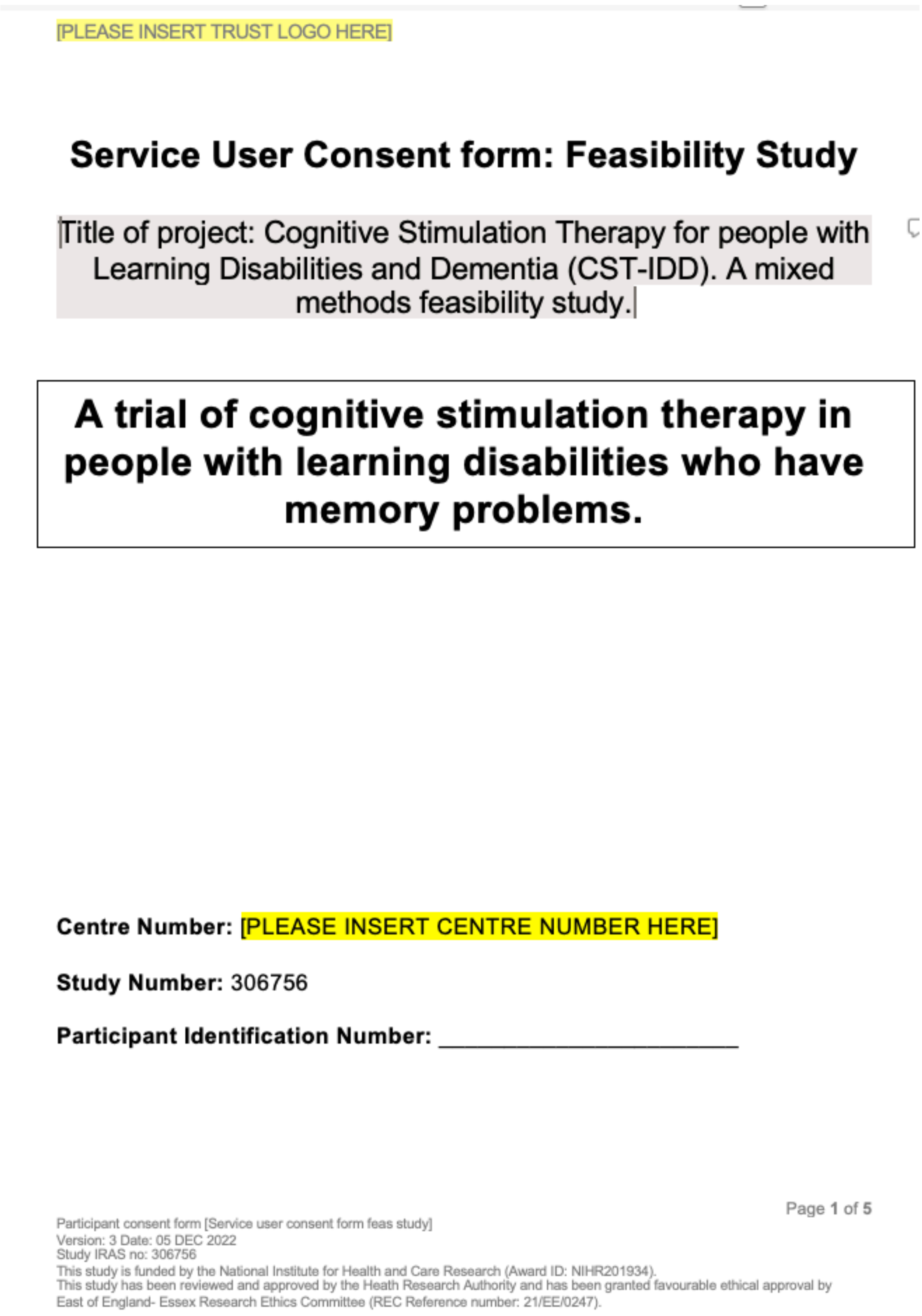
 	You can call me if you are not happy with the study. My phone number is: [PLEASE YOUR WORK NUMBER HERE]

Thank you for looking at this.

This research project has been reviewed and approved by East of England- Essex Research Ethics Committee who are there to make sure you are treated well.

Appendix F

Group Participant Consent Form



[PLEASE INSERT TRUST LOGO HERE]

Service User Consent form: Feasibility Study

Title of project: Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

A trial of cognitive stimulation therapy in people with learning disabilities who have memory problems.

Centre Number: [PLEASE INSERT CENTRE NUMBER HERE]

Study Number: 306756

Participant Identification Number: ________________________

Participant consent form [Service user consent form feas study]
Version: 3 Date: 05 DEC 2022
Study IRAS no: 306756
This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934).
This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

[PLEASE INSERT TRUST LOGO HERE]

		NO	YES
Please answer tick one box:		✗	✓
	I have read the information sheet about the research. Version: 4 Date: 6th December 2022		
	I can understand the things the information sheet told me.		
	I was able to ask questions if I wanted to.		
	I understand that it is my choice to take part in this study.		
	I understand that I can say **No** at any time if I want to stop.		

This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934).
This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

[PLEASE INSERT TRUST LOGO HERE]

		NO	YES
Please answer tick one box:			
	I agree to my GP (doctor) being told I am taking part.		
	I understand that some of my sessions will be audiotaped.		
	**OPTIONAL** I agree to take part in an interview at the end of the sessions.		
	I am happy to take part in the study.		

[PLEASE INSERT TRUST LOGO HERE]

Name:	
	
Date (DD/MMM/YYYY):	
	________/________/_________
Signature:	

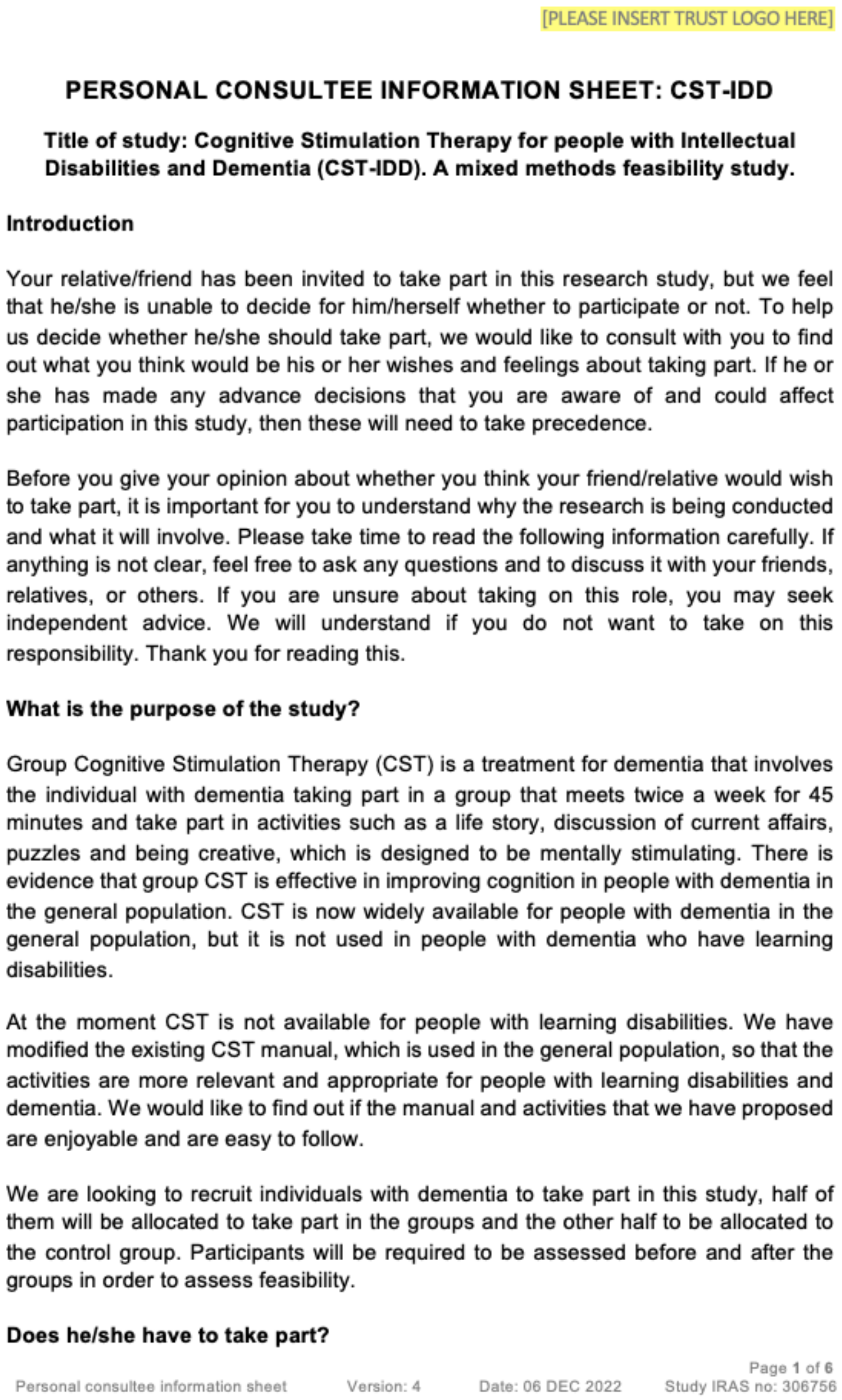
[PLEASE INSERT TRUST LOGO HERE]

Researchers name:	
	
Date (DD/MMM/YYYY):	
	______/______/______
Signature:	

When completed: 1 copy for participant; 1 copy for the care record; 1 (original) for the research file.

Appendix G

Personal Consultee Information Sheet



[PLEASE INSERT TRUST LOGO HERE]

PERSONAL CONSULTEE INFORMATION SHEET: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Introduction

Your relative/friend has been invited to take part in this research study, but we feel that he/she is unable to decide for him/herself whether to participate or not. To help us decide whether he/she should take part, we would like to consult with you to find out what you think would be his or her wishes and feelings about taking part. If he or she has made any advance decisions that you are aware of and could affect participation in this study, then these will need to take precedence.

Before you give your opinion about whether you think your friend/relative would wish to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. If anything is not clear, feel free to ask any questions and to discuss it with your friends, relatives, or others. If you are unsure about taking on this role, you may seek independent advice. We will understand if you do not want to take on this responsibility. Thank you for reading this.

What is the purpose of the study?

Group Cognitive Stimulation Therapy (CST) is a treatment for dementia that involves the individual with dementia taking part in a group that meets twice a week for 45 minutes and take part in activities such as a life story, discussion of current affairs, puzzles and being creative, which is designed to be mentally stimulating. There is evidence that group CST is effective in improving cognition in people with dementia in the general population. CST is now widely available for people with dementia in the general population, but it is not used in people with dementia who have learning disabilities.

At the moment CST is not available for people with learning disabilities. We have modified the existing CST manual, which is used in the general population, so that the activities are more relevant and appropriate for people with learning disabilities and dementia. We would like to find out if the manual and activities that we have proposed are enjoyable and are easy to follow.

We are looking to recruit individuals with dementia to take part in this study, half of them will be allocated to take part in the groups and the other half to be allocated to the control group. Participants will be required to be assessed before and after the groups in order to assess feasibility.

Does he/she have to take part?

Page **1** of **6**

Personal consultee information sheet Version: 4 Date: 06 DEC 2022 Study IRAS no: 306756

No, it is entirely voluntary whether he or she should take part. If you think that your friend/relative would wish to take part, you will be given this information sheet and asked to sign a Consultee Declaration form.

You are free to withdraw your relative/friend at any time from the study without giving a reason. This will not affect the standard of care that he/she receives, and it will not have any influence on future care that he/she receives.

What will happen if he/she takes part?

If you agree that your friend/relative would wish to take part, his/her carer will be asked to carry out an assessment measuring cognition and quality of life before being randomly allocated to the intervention or control group. Those in the intervention group will be offered the opportunity to take part in a Group CST intervention, those in the control group will carry out their normal activities and be invited to repeat the assessments after 8 weeks. This information will help us to check whether running a large study evaluating the effects of CST is feasible.

Participants in the intervention group may be invited to take part in a short interview at the end of one of the sessions. We will audio-tape and transcribe the interviews. We will remove any information that could identify them from the transcripts and the recording will be deleted from the digital recorder. We may use a Talking Mat during the interview which uses symbols to aid communication. We will take a photo of the symbols on the mat. We will ensure no identifying features will be in the photos and no photos of participants will be taken. The information participants give us will help us check whether the groups were adequately adapted, and if it was enjoyed or not.

What will I have to do?

You will be asked to sign the declaration form if you think that your friend/relative would wish to take part in the study.

What are the possible advantages and disadvantages of taking part?

There are no direct advantages for your friend or relative in taking part. However, by taking part, you he or she will help to potentially shape an intervention, which will then be used as part of a trial, and could be of benefit for future patients. It is very unlikely that any harm should come to your friend or relative in this study.

Will their taking part in this study be kept confidential?

All the information that is collected about your friend or relative during the course of the research will be kept strictly confidential and will not be made available to anyone who is not directly connected with the study. Personal information will not be included on any of the study questionnaires, and instead, he or she will be identified by a study

ID number. There will only be one list that links your study ID number to your name and personal details, and this will be stored on a secure NHS computer with permission-based access. The list that links the ID numbers to their identity will be kept separately from the data. Personal data will be stored for 6-12 months locally by NHS research sites and then archived in line with their trust's policy. Any direct quotations used from recordings will be anonymised.

Although what your friend or relative says to us is confidential, should they disclose anything to us which we feel puts them or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If confidentiality is breached in this way, we will try to manage this situation as sensitively as possible.

How will we use information about them?

We will need to use information about your friend or relative in this research project. This information will include their:

- Name
- Age
- Gender
- Ethnicity
- Contact details (address and telephone numbers)
- Diagnosis
- NHS number

People will use this information to do the research or to check their records to make sure that the research is being done properly. People who do not need to know who they are will not be able to see their name or contact details. Their data will have a code number instead. We will keep all information about them safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that they took part in the study.

What are your choices about how your friend or relative's information is used?

Your friend or relative can stop being part of the study at any time, without giving a reason, but we will keep information about them that we already have. We need to manage your friend or relative's records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about them.

Where can you find out more about how your friend or relatives' information is used?

You can find out more about how we use their information at www.hra.nhs.uk/information-about-patients/

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a peer reviewed journal and presented at conferences but your friend or relative will not be identified. We will produce a summary of the research findings for the participants of the study and can send this to you if you wish.

What will happen if I don't want him or her to carry on with this study?

You are free to withdraw your friend or relative from the study at any time without giving a reason. He or she will not be asked to complete any further questionnaires but the ones they have already completed may still be used.

Who is organising and funding the research?

The study is being organised by Professor Aimee Spector and Dr Afia Ali who are Chief Investigators of the research project. The study is being sponsored by North East London NHS Foundation Trust. The project is funded by the National Institute for Health and Care Research (Award ID: NIHR201934). The National Institute for Health and Care Research will not be involved in the conduct of the study.

Who has reviewed the study?

The study has been reviewed and approved by The Health Research Authority and has also been granted a favourable ethical approval by East of England - Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

What if there is a problem?

If you have any concerns or wish to discuss the project with someone then you can speak to your local research team who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response, then you can contact one of the Chief Investigators (see details below) who will do her best to address the issues. You can also contact the Patient Advice and Liaison Service (PALS) for independent advice (see below). They can give you information about how you can complain formally through the NHS Complaints Procedure. You can also obtain details from your local NHS Trust.

In the event that something goes wrong and your friend or relative is harmed during the research and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from the Trust. However, you may have to pay the legal costs.

Local PALS Telephone number: PLEASE INSERT LOCAL PALS CONTACT NUMBER HERE]

Local PALS Email: PLEASE INSERT LOCAL PALS EMAIL HERE]

Contact details for local research team:

Local Researcher contact details:

- Name: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Address: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Telephone: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Email: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]

Principal Investigator contact details:

- Name: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Address: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Telephone: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Email: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]

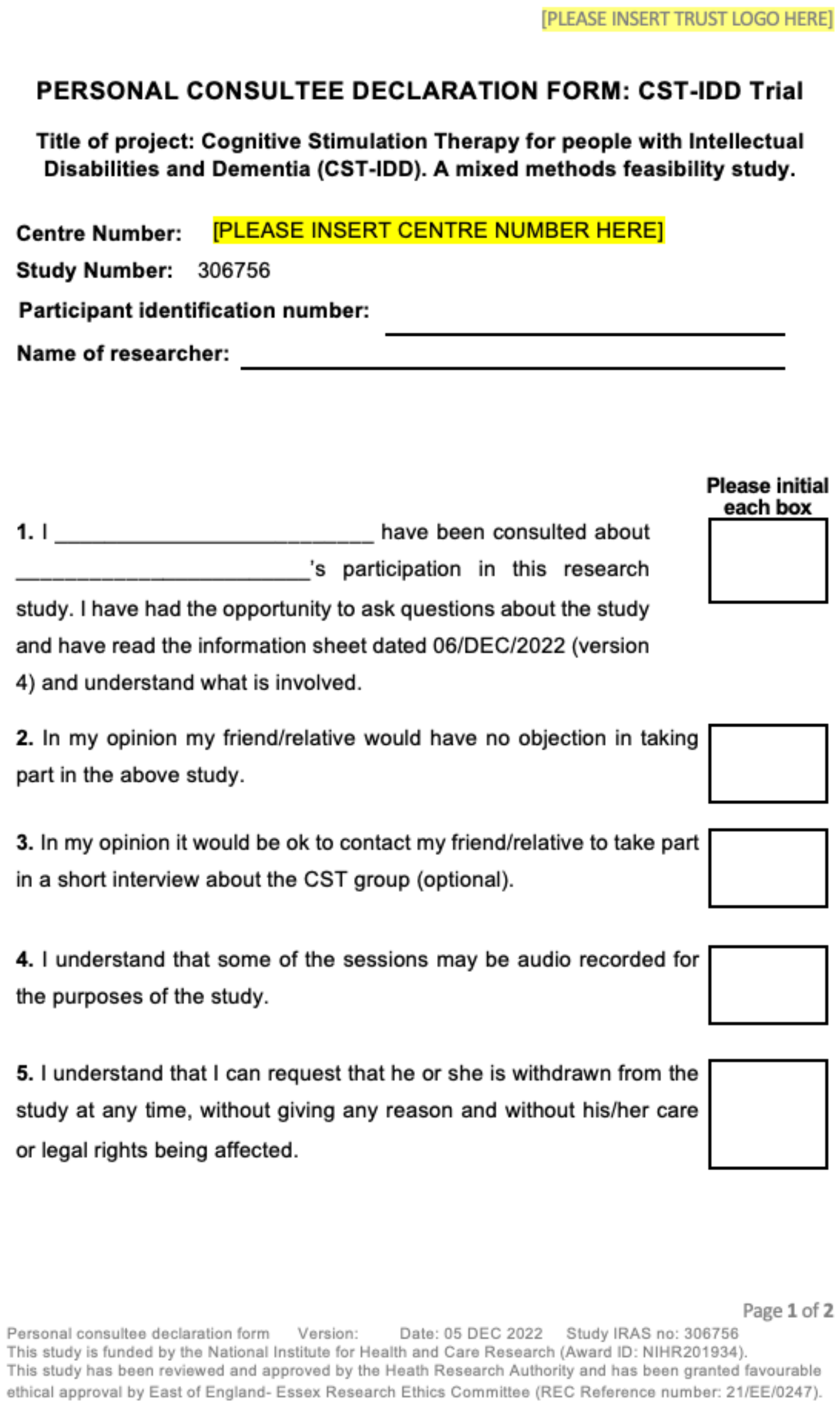
Contact details for Chief Investigators:

Prof Aimee Spector

Dr Afia Ali

Appendix H

Personal Consultee Declaration Form



[PLEASE INSERT TRUST LOGO HERE]

PERSONAL CONSULTEE DECLARATION FORM: CST-IDD Trial

Title of project: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Centre Number: [PLEASE INSERT CENTRE NUMBER HERE]
Study Number: 306756
Participant identification number: ____________________
Name of researcher: ____________________

	Please initial each box
1. I ____________________________ have been consulted about __________________________'s participation in this research study. I have had the opportunity to ask questions about the study and have read the information sheet dated 06/DEC/2022 (version 4) and understand what is involved.	☐
2. In my opinion my friend/relative would have no objection in taking part in the above study.	☐
3. In my opinion it would be ok to contact my friend/relative to take part in a short interview about the CST group (optional).	☐
4. I understand that some of the sessions may be audio recorded for the purposes of the study.	☐
5. I understand that I can request that he or she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.	☐

Page **1** of **2**

Personal consultee declaration form Version: Date: 05 DEC 2022 Study IRAS no: 306756
This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934).
This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

6. I understand that relevant sections of his/her care records and data collected during the study may be looked at by responsible individuals from regulatory authorities. ☐

7. In my opinion it would be ok for the GP to be informed of his/her participation. ☐

8. In my opinion I think my relative/friend would wish to take part in this research study. ☐

Name of consultee: ______________________________

Relationship to participant: ______________________________

Date (DD/MMM/YYYY): ______________________________

Name of person undertaking consultation: ______________________________

Date (DD/MMM/YYYY): ______________________________

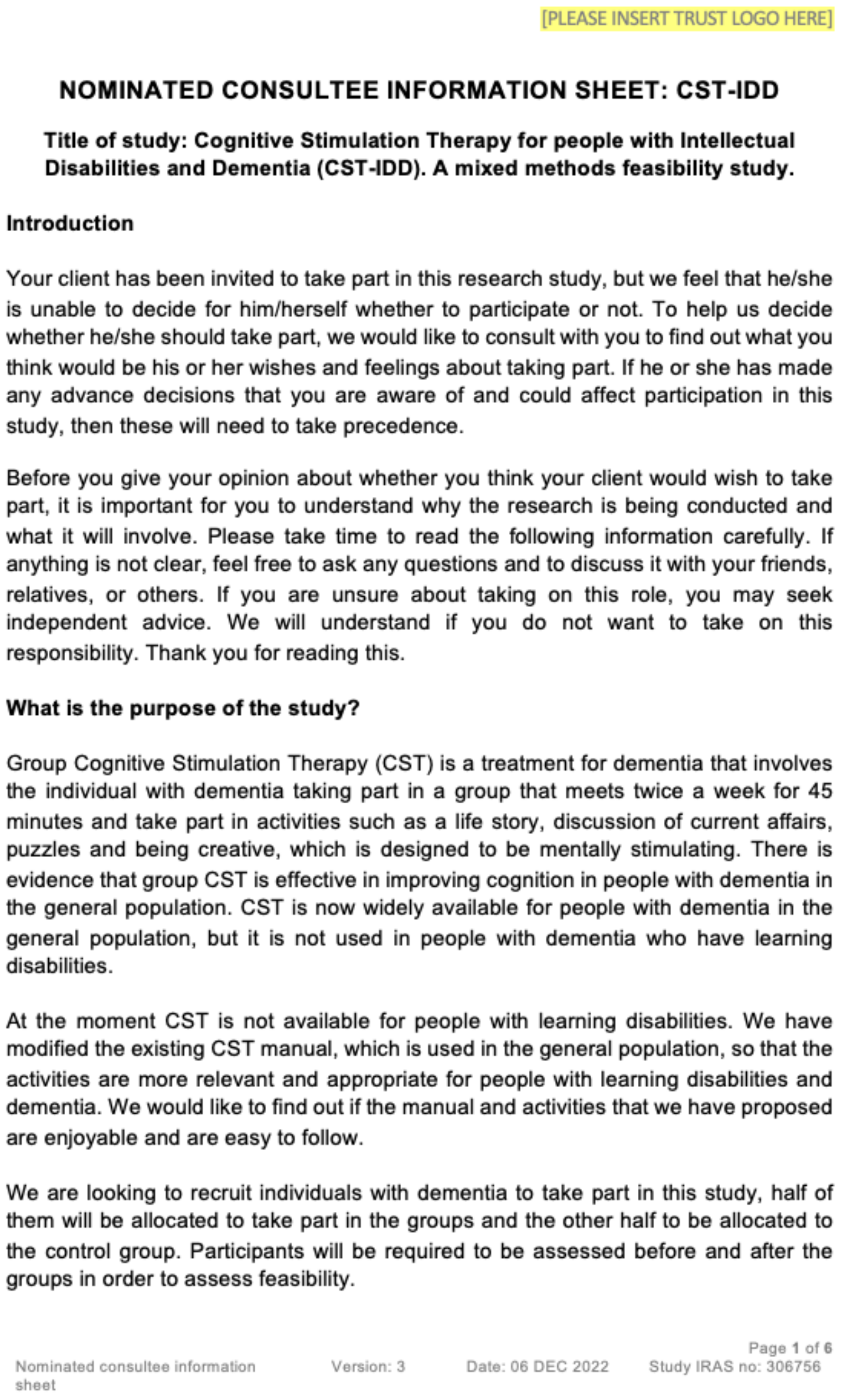
Signature: ______________________________

When completed: 1 copy for consultee; 1 copy for the care record; 1 (original) for the research file.

This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934).
This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

Appendix I

Nominated Consultee Information Sheet



[PLEASE INSERT TRUST LOGO HERE]

NOMINATED CONSULTEE INFORMATION SHEET: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Introduction

Your client has been invited to take part in this research study, but we feel that he/she is unable to decide for him/herself whether to participate or not. To help us decide whether he/she should take part, we would like to consult with you to find out what you think would be his or her wishes and feelings about taking part. If he or she has made any advance decisions that you are aware of and could affect participation in this study, then these will need to take precedence.

Before you give your opinion about whether you think your client would wish to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. If anything is not clear, feel free to ask any questions and to discuss it with your friends, relatives, or others. If you are unsure about taking on this role, you may seek independent advice. We will understand if you do not want to take on this responsibility. Thank you for reading this.

What is the purpose of the study?

Group Cognitive Stimulation Therapy (CST) is a treatment for dementia that involves the individual with dementia taking part in a group that meets twice a week for 45 minutes and take part in activities such as a life story, discussion of current affairs, puzzles and being creative, which is designed to be mentally stimulating. There is evidence that group CST is effective in improving cognition in people with dementia in the general population. CST is now widely available for people with dementia in the general population, but it is not used in people with dementia who have learning disabilities.

At the moment CST is not available for people with learning disabilities. We have modified the existing CST manual, which is used in the general population, so that the activities are more relevant and appropriate for people with learning disabilities and dementia. We would like to find out if the manual and activities that we have proposed are enjoyable and are easy to follow.

We are looking to recruit individuals with dementia to take part in this study, half of them will be allocated to take part in the groups and the other half to be allocated to the control group. Participants will be required to be assessed before and after the groups in order to assess feasibility.

Does he/she have to take part?

No, it is entirely voluntary whether he or she should take part. If you think that your client would wish to take part, you will be given this information sheet and asked to sign a Consultee Declaration form.

You are free to withdraw your client at any time from the study without giving a reason. This will not affect the standard of care that he/she receives, and it will not have any influence on future care that he/she receives.

What will happen if he/she takes part?

If you agree that your client would wish to take part, his/her carer will be asked to carry out an assessment measuring cognition and quality of life before being randomly allocated to the intervention or control group. Those in the intervention group will be offered the opportunity to take part in a Group CST intervention, those in the control group will carry out their normal activities and be invited to repeat the assessments after 8 weeks. This information will help us to check whether running a large study evaluating the effects of CST is feasible.

Participants in the intervention group may be invited to take part in a short interview at the end of one of the sessions. We will audio-tape and transcribe the interviews. We will remove any information that could identify them from the transcripts and the recording will be deleted from the digital recorder. We may use a Talking Mat during the interview which uses symbols to aid communication. We will take a photo of the symbols on the mat. We will ensure no identifying features will be in the photos and no photos of participants will be taken. The information participants give us will help us check whether the groups were adequately adapted, and if it was enjoyed or not.

What will I have to do?

You will be asked to sign the declaration form if you think that your client would wish to take part in the study.

What are the possible advantages and disadvantages of taking part?

There are no direct advantages for your client in taking part. However, by taking part, he or she will help to potentially shape an intervention, which will then be used as part of a trial and could be of benefit for future patients. It is very unlikely that any harm should come to your client in this study.

Will their taking part in this study be kept confidential?

All the information that is collected about your client during the course of the research will be kept strictly confidential and will not be made available to anyone who is not directly connected with the study. Personal information will not be included on any of the study questionnaires, and instead, he or she will be identified by a study ID number. There will only be one list that links your study ID number to your name and personal details, and this will be stored on a secure NHS computer with permission-based access. The list that links the ID numbers to their identity will be kept separately from the data. Personal data will be stored for 6-12 months locally by NHS research sites and then archived in line with their trust's policy. Any direct quotations from recordings that are used will be anonymised.

Although what your client says to us is confidential, should they disclose anything to us which we feel puts them or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If we have to breach confidentiality in this way you will be informed, and we will try to manage these situations as sensitively as possible.

How will we use information about them?

We will need to use information about your client in this research project. This information will include their:

- Name
- Age
- Gender
- Ethnicity
- Contact details (address and telephone numbers)
- Diagnosis
- NHS number

People will use this information to do the research or to check their records to make sure that the research is being done properly. People who do not need to know who they are, will not be able to see their name or contact details. Their data will have a code number instead. We will keep all information about them safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that they took part in the study

What are your choices about how your client's information is used?

Your client can stop being part of the study at any time, without giving a reason, but we will keep information about them that we already have. We need to manage your client's records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about them.

Where can you find out more about how your client's information is used?

You can find out more about how we use their information at www.hra.nhs.uk/information-about-patients/

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a peer reviewed journal and presented at conferences, but your client will not be identified. We will produce a summary of the research findings for the participants of the study and can send this to you if you wish.

What will happen if I don't want him or her to carry on with this study?

You are free to withdraw your client from the study at any time without giving a reason. He or she will not be asked to complete any further questionnaires but the ones they have already completed may still be used.

Who is organising and funding the research?

The study is being organised by Professor Aimee Spector and Dr Afia Ali who are Chief Investigators of the research project. The study is being sponsored by North East London NHS Foundation Trust. The project is funded by the National Institute for Health and Care Research (Award ID: NIHR201934). The National Institute for Health and Care Research will not be involved in the conduct of the study.

Who has reviewed the study?

The study has been reviewed and approved by the Heath Research Authority and has also been granted favourable ethical approval by East of England - Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

What if there is a problem?

If you have any concerns or wish to discuss the project with someone then you can speak to your local research team who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response, then you can contact one of the Chief Investigator (see details below) who will do her best to address the issues. You can also contact the Patient Advice and Liaison Service (PALS) for independent advice (see below). They can give you information about how you can complain formally through the NHS Complaints Procedure. You can also obtain details from your local NHS Trust.

In the event that something goes wrong, and your client is harmed during the research, and this is due to someone's negligence, then you may have grounds for legal action

In order to obtain compensation from the Trust. However, you may have to pay the legal costs.

Local PALS Telephone number: [PLEASE INSERT LOCAL PALS CONTACT NUMBER HERE
Local PALS email: [PLEASE INSERT LOCAL PALS EMAIL HERE]

<u>Contact details for local research team:</u>

Local Researcher contact details:

- Name: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Address: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Telephone: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Email: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]

Principal Investigator contact details:

- Name: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Address: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Telephone: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Email: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]

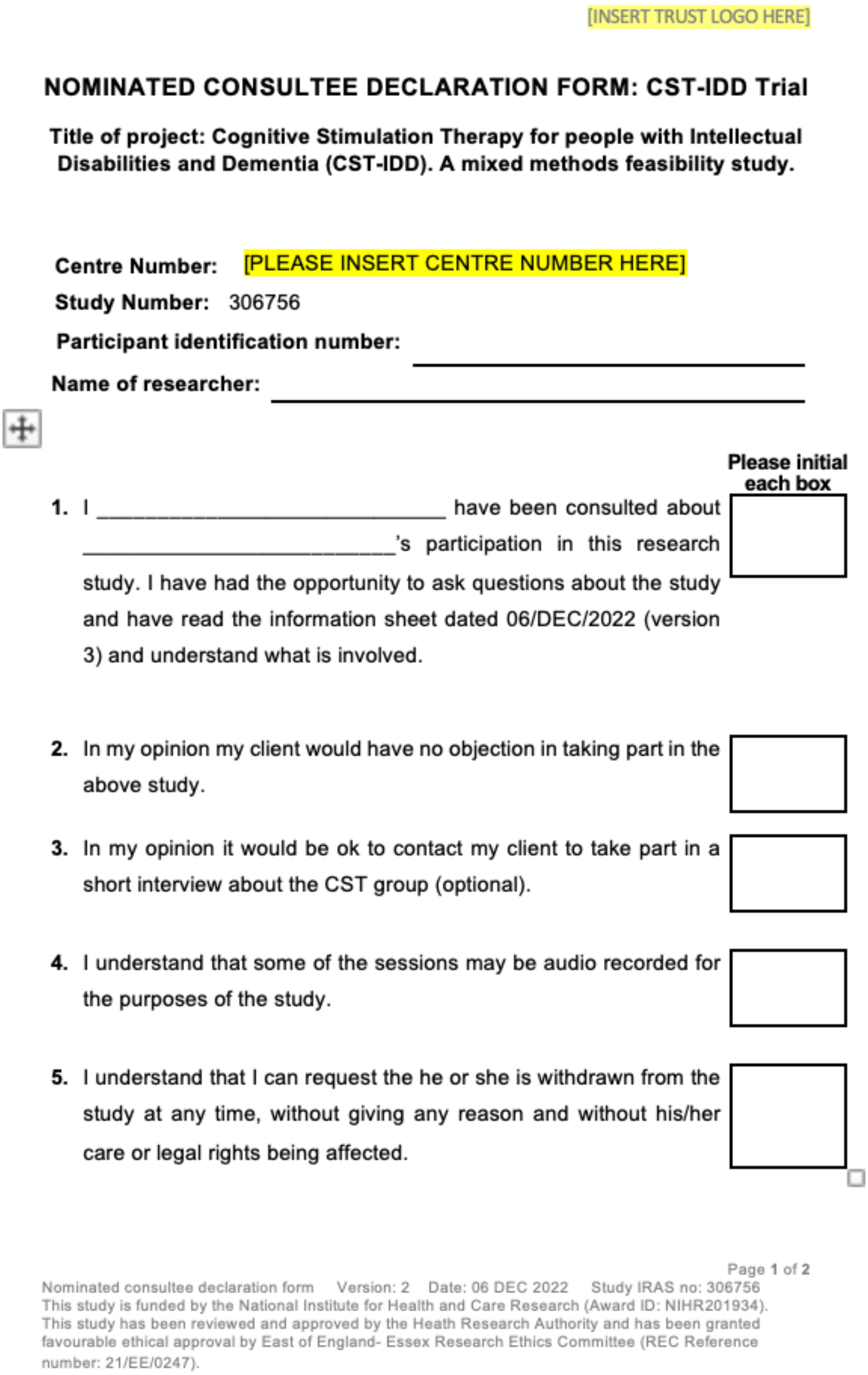
<u>Contact details for Chief Investigators:</u>

Prof Aimee Spector

Dr Afia Ali

Appendix J

Nominated Consultee Declaration Form



[INSERT TRUST LOGO HERE]

NOMINATED CONSULTEE DECLARATION FORM: CST-IDD Trial

Title of project: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Centre Number: [PLEASE INSERT CENTRE NUMBER HERE]
Study Number: 306756
Participant identification number: ______________________
Name of researcher: ______________________

Please initial each box

1. I ______________________ have been consulted about ______________________'s participation in this research study. I have had the opportunity to ask questions about the study and have read the information sheet dated 06/DEC/2022 (version 3) and understand what is involved. ☐
2. In my opinion my client would have no objection in taking part in the above study. ☐
3. In my opinion it would be ok to contact my client to take part in a short interview about the CST group (optional). ☐
4. I understand that some of the sessions may be audio recorded for the purposes of the study. ☐
5. I understand that I can request the he or she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected. ☐

Page **1** of **2**

Nominated consultee declaration form Version: 2 Date: 06 DEC 2022 Study IRAS no: 306756

This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934). This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

6. I understand that relevant sections of his/her care records and data collected during the study may be looked at by responsible individuals from regulatory authorities. ☐

7. In my opinion it would be ok for the GP to be informed of his/her participation. ☐

8. In my opinion I think my client would wish to take part in this research study. ☐

Name of consultee: ____________________

Relationship to participant: ____________________

Date (DD/MMM/YYYY): ____________________

Signature: ____________________

Name of person undertaking consultation: ____________________

Date (DD/MMM/YYYY): ____________________

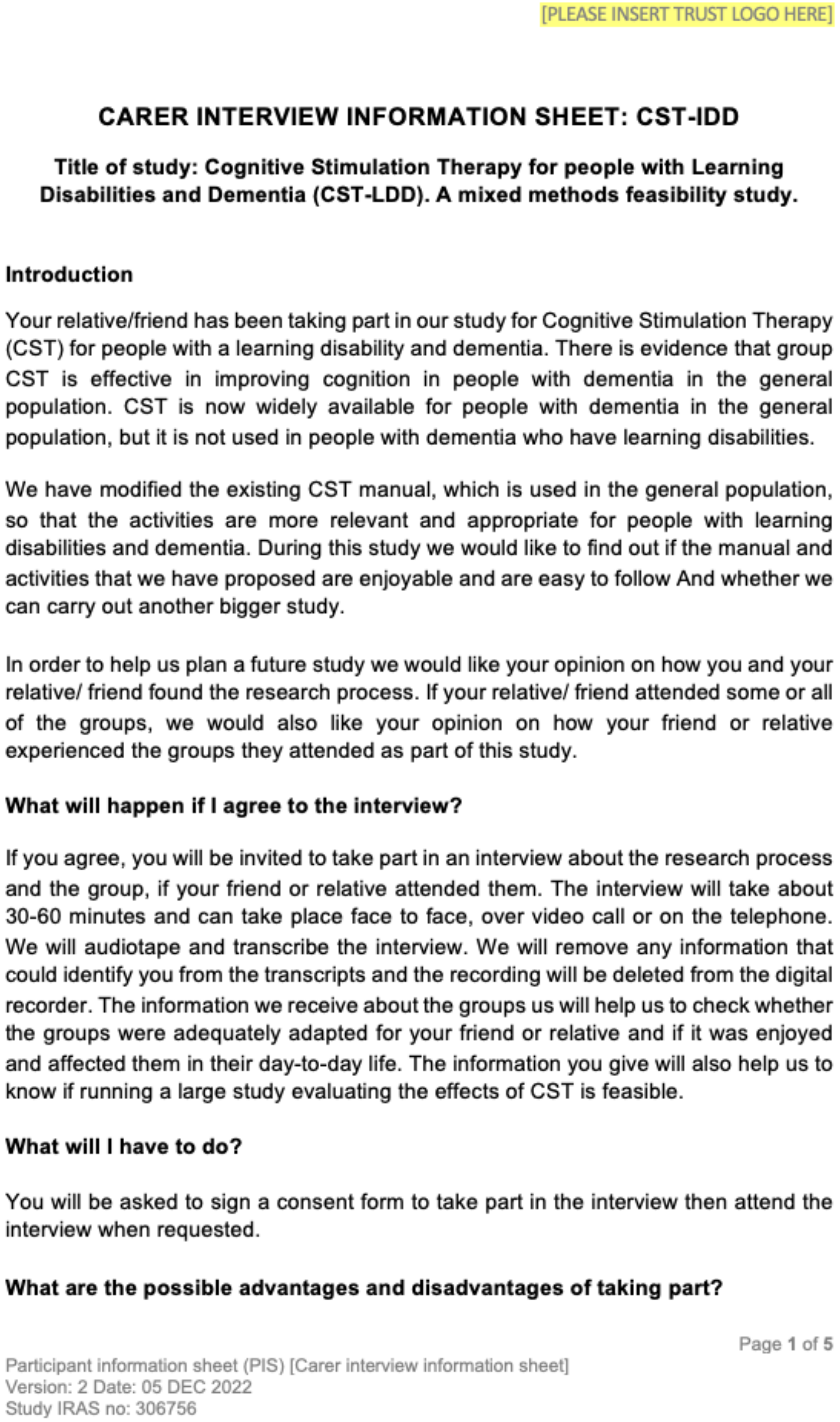
Signature: ____________________

When completed: 1 copy for consultee; 1 copy for the care record; 1 (original) for the research file

This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934).
This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

Appendix K

Carer Information Sheet for Interview



[PLEASE INSERT TRUST LOGO HERE]

CARER INTERVIEW INFORMATION SHEET: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-LDD). A mixed methods feasibility study.

Introduction

Your relative/friend has been taking part in our study for Cognitive Stimulation Therapy (CST) for people with a learning disability and dementia. There is evidence that group CST is effective in improving cognition in people with dementia in the general population. CST is now widely available for people with dementia in the general population, but it is not used in people with dementia who have learning disabilities.

We have modified the existing CST manual, which is used in the general population, so that the activities are more relevant and appropriate for people with learning disabilities and dementia. During this study we would like to find out if the manual and activities that we have proposed are enjoyable and are easy to follow And whether we can carry out another bigger study.

In order to help us plan a future study we would like your opinion on how you and your relative/ friend found the research process. If your relative/ friend attended some or all of the groups, we would also like your opinion on how your friend or relative experienced the groups they attended as part of this study.

What will happen if I agree to the interview?

If you agree, you will be invited to take part in an interview about the research process and the group, if your friend or relative attended them. The interview will take about 30-60 minutes and can take place face to face, over video call or on the telephone. We will audiotape and transcribe the interview. We will remove any information that could identify you from the transcripts and the recording will be deleted from the digital recorder. The information we receive about the groups us will help us to check whether the groups were adequately adapted for your friend or relative and if it was enjoyed and affected them in their day-to-day life. The information you give will also help us to know if running a large study evaluating the effects of CST is feasible.

What will I have to do?

You will be asked to sign a consent form to take part in the interview then attend the interview when requested.

What are the possible advantages and disadvantages of taking part?

Page 1 of 5

Participant information sheet (PIS) [Carer interview information sheet]
Version: 2 Date: 05 DEC 2022
Study IRAS no: 306756

There are no direct advantages for you in taking part. However, by taking part, you will help to potentially shape an intervention, which will then be used as part of a trial and could be of benefit for future patients. It is very unlikely that any harm should come to you in this study.

Will my taking part in this study be kept confidential?

All the information that is collected about you during the course of the research will be kept strictly confidential and will not be made available to anyone who is not directly connected with the study. Personal information will not be included on any of the study questionnaires, and instead, you will be identified by a study ID number. There will only be one list that links your study ID number to your name and personal details, and this will be kept in a locked cabinet, within a locked room. The list that links the ID numbers to your identity will be kept separately from the data. Personal data will be stored for 6-12 months locally by NHS research sites and then archived in line with their trust's policy. Any quotations used from the interview will be anonymised in the final report or any publications.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If we have to breach confidentiality in this way you will be informed, and we will try to manage these situations as sensitively as possible.

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a scientific journal and presented at conferences, but you will not be identified. We will produce a summary of the research findings for the participants of the study and can send this to you if you wish.

How will we use information about you?

We will need to use information from you for this research project. This information will include your:

- Name
- Age
- Gender
- Ethnicity
- Contact details (address and telephone numbers)

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have an ID number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What will happen if I don't want to carry on with this study?

You are free to withdraw from the study at any time without giving a reason.

Who is organising and funding the research?

The study is being organised by Professor Aimee Spector and DR Afia Ali who are Chief Investigators of the research project. The study is being sponsored by North-East London NHS Foundation Trust. The study is funded by the National Institute of and Care Health Research (Award ID: NIHR201934). The National Institute of and Care Health Research will not be involved in the conduct of the study.

Who has reviewed the study?

The study has been reviewed and approved by the Health Research Authority and has also been given favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/02/47).

What if there is a problem?

If you have any concerns or wish to discuss the project with someone then you can speak to your local research team who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response, then you can contact one of the Chief Investigator (see details below) who will do her best to address the issues. You can also contact the Patient Advice and Liaison Service (PALS) for independent advice (see below). They can give you information about how you can complain formally through the NHS Complaints Procedure. You can also obtain details from your local NHS Trust.

In the event that something goes wrong, and you are harmed during the research, and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from the Trust. However, you may have to pay the legal costs.

Local PALS telephone number: PLEASE INSERT LOCAL PALS CONTACT NUMBER HERE]
Local PALS email: PLEASE INSERT LOCAL PALS EMAIL HERE]

Contact details for local research team:

Local Researcher contact details:

- Name: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Address: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Telephone: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Email: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]

Principal Investigator contact details:

- Name: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Address: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Telephone: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]
- Email: [PLEASE INSERT CONTACT DETAILS FOR LOCAL RESEARCH TEAM HERE]

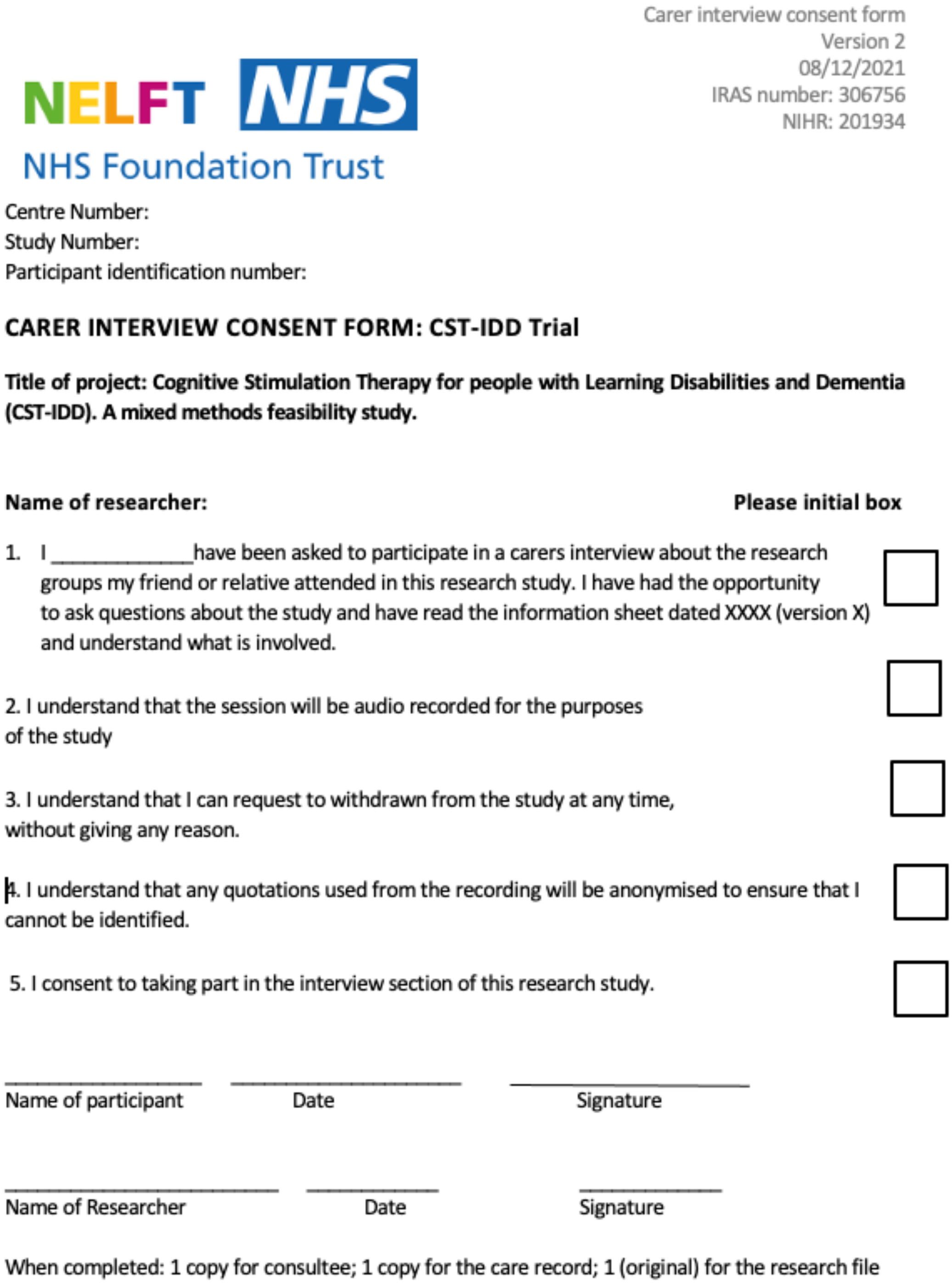
Contact details for Chief Investigators:

Prof Aimee Spector

Dr Afia Ali

Appendix L

Carer Consent Form for Interview



Carer interview consent form
Version 2
08/12/2021
IRAS number: 306756
NIHR: 201934

NELFT NHS
NHS Foundation Trust

Centre Number:
Study Number:
Participant identification number:

CARER INTERVIEW CONSENT FORM: CST-IDD Trial

Title of project: Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Name of researcher: **Please initial box**

1. I ____________have been asked to participate in a carers interview about the research groups my friend or relative attended in this research study. I have had the opportunity to ask questions about the study and have read the information sheet dated XXXX (version X) and understand what is involved. ☐

2. I understand that the session will be audio recorded for the purposes of the study ☐

3. I understand that I can request to withdrawn from the study at any time, without giving any reason. ☐

4. I understand that any quotations used from the recording will be anonymised to ensure that I cannot be identified. ☐

5. I consent to taking part in the interview section of this research study. ☐

_________________ _____________________ _____________________
Name of participant Date Signature

________________________ ___________ ____________
Name of Researcher Date Signature

When completed: 1 copy for consultee; 1 copy for the care record; 1 (original) for the research file

Appendix M

Group Facilitator Information Sheet

UCL

NELFT NHS
NHS Foundation Trust

FACILITATOR QUALITATIVE INTERVIEW INFORMATION SHEET: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Introduction

There is evidence that Group Cognitive Stimulation Therapy (CST) is effective in improving cognition in people with dementia in the general population. CST is now widely available for people with dementia in the general population, but it is not used in people with dementia who have learning disabilities.

We have modified the existing CST manual, which is used in the general population, so that the activities are more relevant and appropriate for people with learning disabilities and dementia. We would like to find out if the manual and activities that we have proposed are feasible and acceptable.

We would like your opinion on how participants experienced the groups they attended as part of this study and your experience of running the groups. The information you give us will help us to check whether the groups were adequately adapted for the participants and if it was enjoyed and affected them in their day-to-day life. It will also help us to know if running a large study evaluating the effects of CST is feasible.

What will happen if I agree to the interview?

If you agree you will be invited to take part in an interview. The interview will take about 30-60 minutes and can take place face to face, on the telephone or video call. We will audiotape and transcribe the interview. We will remove any information that could identify you, the group participants or carers from the transcripts and the recording will be deleted from the digital recorder.

What will I have to do?

You will be asked to sign a consent form to take part in the interview then attend the interview when requested.

What are the possible advantages and disadvantages of taking part?

There are no direct advantages for you in taking part. However, by taking part, you will help to potentially shape an intervention, which will then be used as part of a trial and could be of benefit for future patients. It is very unlikely that any harm should come to you in this study.

Will my taking part in this study be kept confidential?

All the information that is collected about you during the course of the research will be kept strictly confidential and will not be made available to anyone who is not directly connected with the study. Your information will be identified by a study ID number. There will only be one list that links your study ID number to your name and personal details, and this will be stored on a secure NHS computer with permission-based access. The list that links the ID numbers to your identity will be kept separately from the data. Personal data will be stored for 6-12 months locally by NHS research sites and then archived in line with their trust's policy. Any quotations used from the interview will be anonymised in the final report or any publications.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. If we have to breach confidentiality in this way you will be informed, and we will try to manage these situations as sensitively as possible.

What will happen to the results of the research?

The study will be registered on a public web-based database where the study design and results can be viewed. The results of the trial will also be published in a scientific journal and presented at conferences, but you will not be identified. We will produce a summary of the research findings for the participants of the study and can send this to you if you wish.

How will we use information about you?

We will need to use information from you for this research project. This information will include your

- Name
- Age
- Gender
- Ethnicity
- Contact details (work address and telephone number, as well as email address if video call)
- Occupation

People who do not need to know who you are will not be able to see your name or contact details. Your data will have an ID number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study

What will happen if I don't want to carry on with this study?

You are free to withdraw from the study at any time without giving a reason.

Who is organising and funding the research?

The study is being organised by Professor Aimee Spector and Dr Afia Ali who are the Chief Investigators of the research project. The study is being sponsored by North East London NHS Foundation Trust. It is funded by the National Institute of Health and Care Research (Award ID: NIHR201934). The National Institute of Health and Care Research will not be involved in the conduct of the study.

Who has reviewed the study?

The study has been reviewed and approved by the Health Research Authority and has also been given favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/02/47).

What if there is a problem?

If you have any concerns or wish to discuss the project with someone then you can speak to the researcher conducting these interviews or your local research team who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response, then you can contact one of the Chief Investigators (see details below) who will do her best to address the issues. You can also follow your local procedure in your NHS Trust to raise a concern or make a complaint.

In the event that something goes wrong, and you are harmed during the research and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from the Trust. However, you may have to pay the legal costs.

Local PALS Telephone number: 0300 300 1711
Local PALS email: nelftpals@nelft.nhs.uk

Contact details for local research team:

Local Researcher contact details:

- Name: Sarah Hoare
- Address: R&D Department, 1st Floor Maggie Lilley Suite, Goodmayes Hospital, 157 Barley Lane, Goodmayes, Ilford, IG3 8XJ
- Telephone: 0300 555 1200 Ext: 54048
- Email: sarah.hoare@nelft.nhs.uk

Principal Investigator contact details:

What will happen if I don't want to carry on with this study?

You are free to withdraw from the study at any time without giving a reason.

Who is organising and funding the research?

The study is being organised by Professor Aimee Spector and Dr Afia Ali who are the Chief Investigators of the research project. The study is being sponsored by North East London NHS Foundation Trust. It is funded by the National Institute of Health and Care Research (Award ID: NIHR201934). The National Institute of Health and Care Research will not be involved in the conduct of the study.

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If you have any concerns or wish to discuss the project with someone then you can speak to the researcher conducting these interviews or your local research team who will do their best to answer your question or resolve any difficulties that you have. If you are not satisfied with the response, then you can contact one of the Chief Investigators (see details below) who will do her best to address the issues. You can also follow your local procedure in your NHS Trust to raise a concern or make a complaint.

In the event that something goes wrong, and you are harmed during the research and this is due to someone's negligence, then you may have grounds for legal action in order to obtain compensation from the Trust. However, you may have to pay the legal costs.
Local PALS Telephone number: 0300 300 1711
Local PALS email: nelftpals@nelft.nhs.uk

Contact details for local research team:

Local Researcher contact details:

- Name: Sarah Hoare
- Address: R&D Department, 1st Floor Maggie Lilley Suite, Goodmayes Hospital, 157 Barley Lane, Goodmayes, Ilford, IG3 8XJ
- Telephone: 0300 555 1200 Ext: 54048
- Email: sarah.hoare@nelft.nhs.uk

Principal Investigator contact details:

Appendix N

Group Facilitator Consent Form

UCL

NELFT NHS
NHS Foundation Trust

FACILITATOR QUALITATIVE INTERVIEW CONSENT FORM: CST-IDD Trial

Title of project: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Centre Number: 1
Study Number: 306756
Participant (facilitator) identification number: ________________

Name of researcher: ________________

Please initial each box:

1. I ___________________________have been asked to participate in a facilitator interview about the group(s) I have been facilitating in this research study. I have had the opportunity to ask questions about the study and have read the information sheet dated ____/____/______ (version_____) and understand what is involved. ☐
2. I understand that the session will be audio recorded for the purposes of the study. ☐
3. I understand that I can request to withdrawn from the study at any time, without giving any reason. ☐
4. I understand that any quotations used from the recording will be anonymised to ensure that I cannot be identified. ☐
5. I consent to taking part in the interview section of this research study. ☐

Name of participant (facilitator): ________________________________

Date (DD/MMM/YYYY): ________________________________

Signature: ________________________________

Name of researcher: ________________________________

Date (DD/MMM/YYYY): ________________________________

Signature: ________________________________

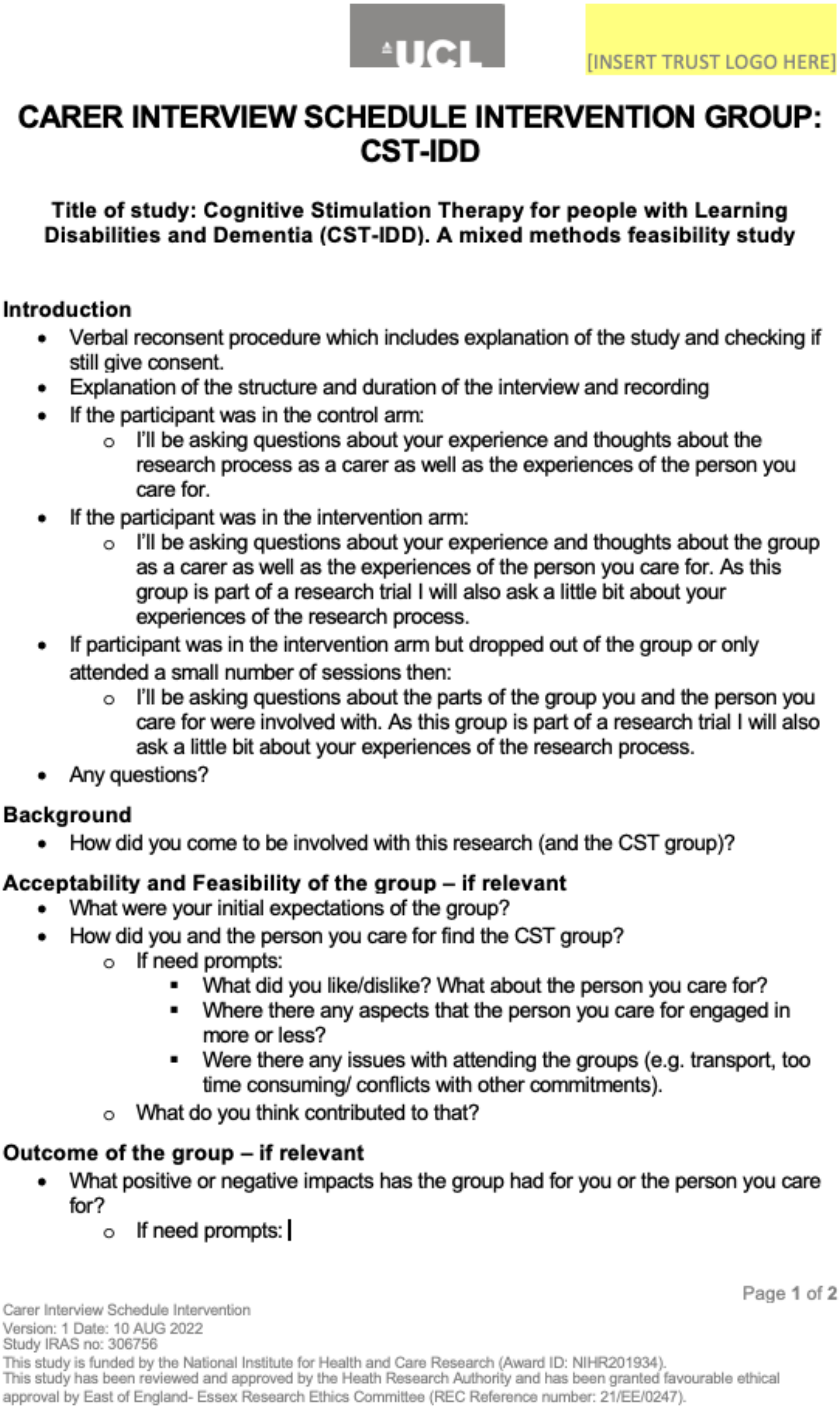
When completed: 1 copy for facilitator; 1 (original) for the research file.

Page 1 of 1

Facilitator Qualitative Interview Consent Form Version: 1 Date: 21 JUN 2022 Study IRAS no: 306756
This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934).
This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

Appendix O

Carer Interview Schedule



UCL

[INSERT TRUST LOGO HERE]

CARER INTERVIEW SCHEDULE INTERVENTION GROUP: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-IDD). A mixed methods feasibility study

Introduction

- Verbal reconsent procedure which includes explanation of the study and checking if still give consent.
- Explanation of the structure and duration of the interview and recording
- If the participant was in the control arm:
    - I'll be asking questions about your experience and thoughts about the research process as a carer as well as the experiences of the person you care for.
- If the participant was in the intervention arm:
    - I'll be asking questions about your experience and thoughts about the group as a carer as well as the experiences of the person you care for. As this group is part of a research trial I will also ask a little bit about your experiences of the research process.
- If participant was in the intervention arm but dropped out of the group or only attended a small number of sessions then:
    - I'll be asking questions about the parts of the group you and the person you care for were involved with. As this group is part of a research trial I will also ask a little bit about your experiences of the research process.
- Any questions?

Background

- How did you come to be involved with this research (and the CST group)?

Acceptability and Feasibility of the group – if relevant

- What were your initial expectations of the group?
- How did you and the person you care for find the CST group?
    - If need prompts:
        - What did you like/dislike? What about the person you care for?
        - Where there any aspects that the person you care for engaged in more or less?
        - Were there any issues with attending the groups (e.g. transport, too time consuming/ conflicts with other commitments).
    - What do you think contributed to that?

Outcome of the group – if relevant

- What positive or negative impacts has the group had for you or the person you care for?
    - If need prompts:

This study is funded by the National Institute for Health and Care Research (Award ID: NIHR201934).
This study has been reviewed and approved by the Heath Research Authority and has been granted favourable ethical approval by East of England- Essex Research Ethics Committee (REC Reference number: 21/EE/0247).

        - Have you seen any improvement or deterioration in the person's memory, alertness or behaviour?
    - What do you think contributed to that?

Is there anything that you would change about the CST group if it was to be run again?

- Is there anything else that you would like to say about the CST group?
    - Prompts for the end if haven't covered any of these topics:
        - Any comments on specific sessions, format of the sessions (set up/frequency/length/number of sessions/group size)

Research Process

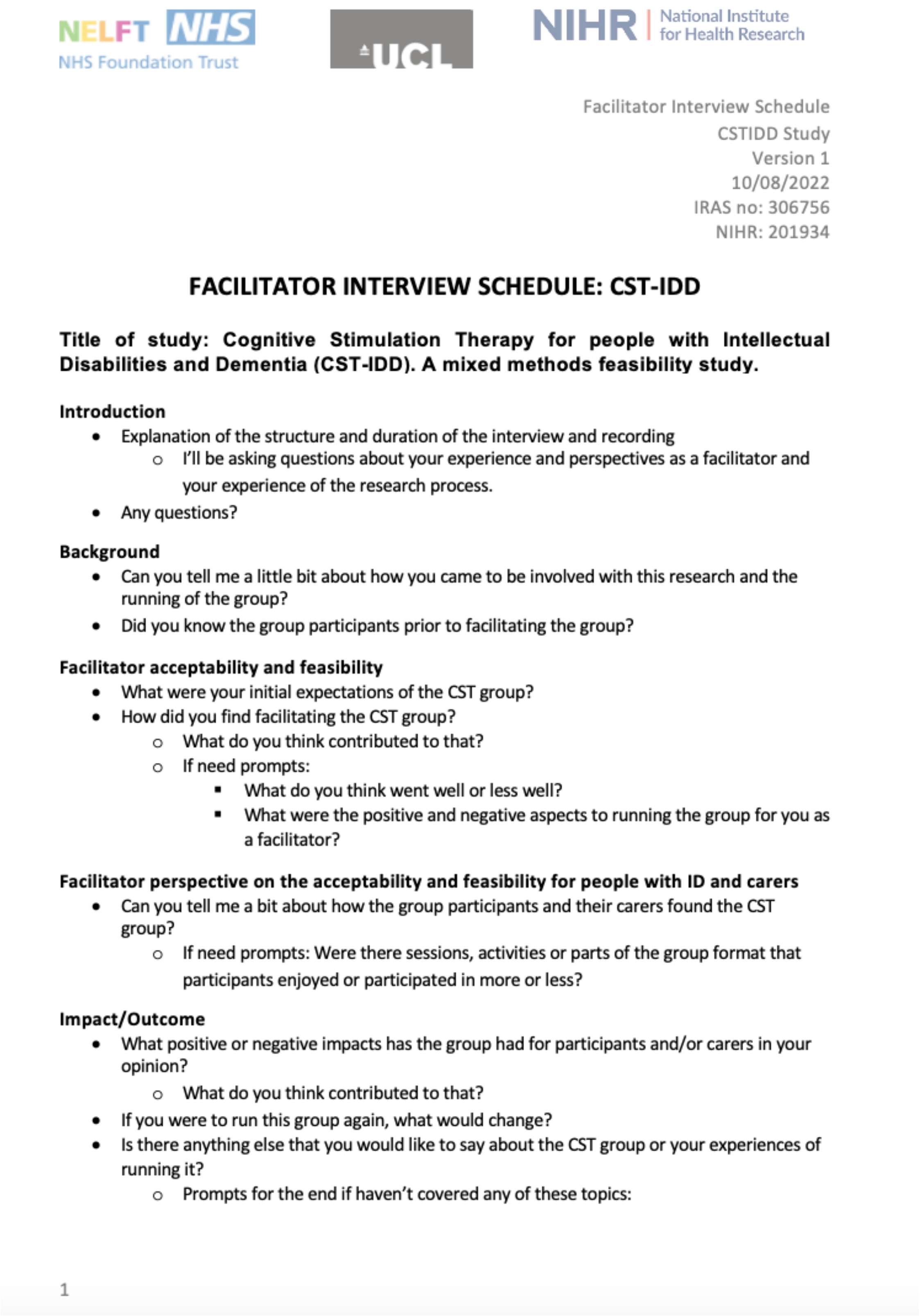
- What were your experiences of the research process?
    - For example, your interaction with the research team and assessors, the information provided about the research or the experience of completing the forms and questionnaires?
- How did the person you care for find the research process?
- Was there anything that you liked or disliked about taking part in the research?
- Was there anything that the person you care for liked or disliked about taking part in the research?
- Were there any issues or challenges in taking part in the research?
- Is there anything else you would like to say about the research process
    - Prompt if haven't covered any of these topics: interaction with research team and assessors, ease of contact, information provided about the research, experience of completing the forms and questionnaires, being able to discuss with someone if had any concerns, time implications.

Ending

- Thank you for your time and information
- Next steps: would you like a copy of the transcript to be sent to you to check?
- A copy of results will be sent to all participants, any further questions?

Appendix P

Group Facilitator Interview Schedule



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UCL

NIHR | National Institute for Health Research

Facilitator Interview Schedule
CSTIDD Study
Version 1
10/08/2022
IRAS no: 306756
NIHR: 201934

FACILITATOR INTERVIEW SCHEDULE: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Introduction

- Explanation of the structure and duration of the interview and recording
    - I'll be asking questions about your experience and perspectives as a facilitator and your experience of the research process.
- Any questions?

Background

- Can you tell me a little bit about how you came to be involved with this research and the running of the group?
- Did you know the group participants prior to facilitating the group?

Facilitator acceptability and feasibility

- What were your initial expectations of the CST group?
- How did you find facilitating the CST group?
    - What do you think contributed to that?
    - If need prompts:
        - What do you think went well or less well?
        - What were the positive and negative aspects to running the group for you as a facilitator?

Facilitator perspective on the acceptability and feasibility for people with ID and carers

- Can you tell me a bit about how the group participants and their carers found the CST group?
    - If need prompts: Were there sessions, activities or parts of the group format that participants enjoyed or participated in more or less?

Impact/Outcome

- What positive or negative impacts has the group had for participants and/or carers in your opinion?
    - What do you think contributed to that?
- If you were to run this group again, what would change?
- Is there anything else that you would like to say about the CST group or your experiences of running it?
    - Prompts for the end if haven't covered any of these topics:

    - Manual and or appendix, specific sessions, format of the sessions (set up/frequency/length/number of sessions/number of people in the group), training received, group dynamics, any challenging situations?

Research Process

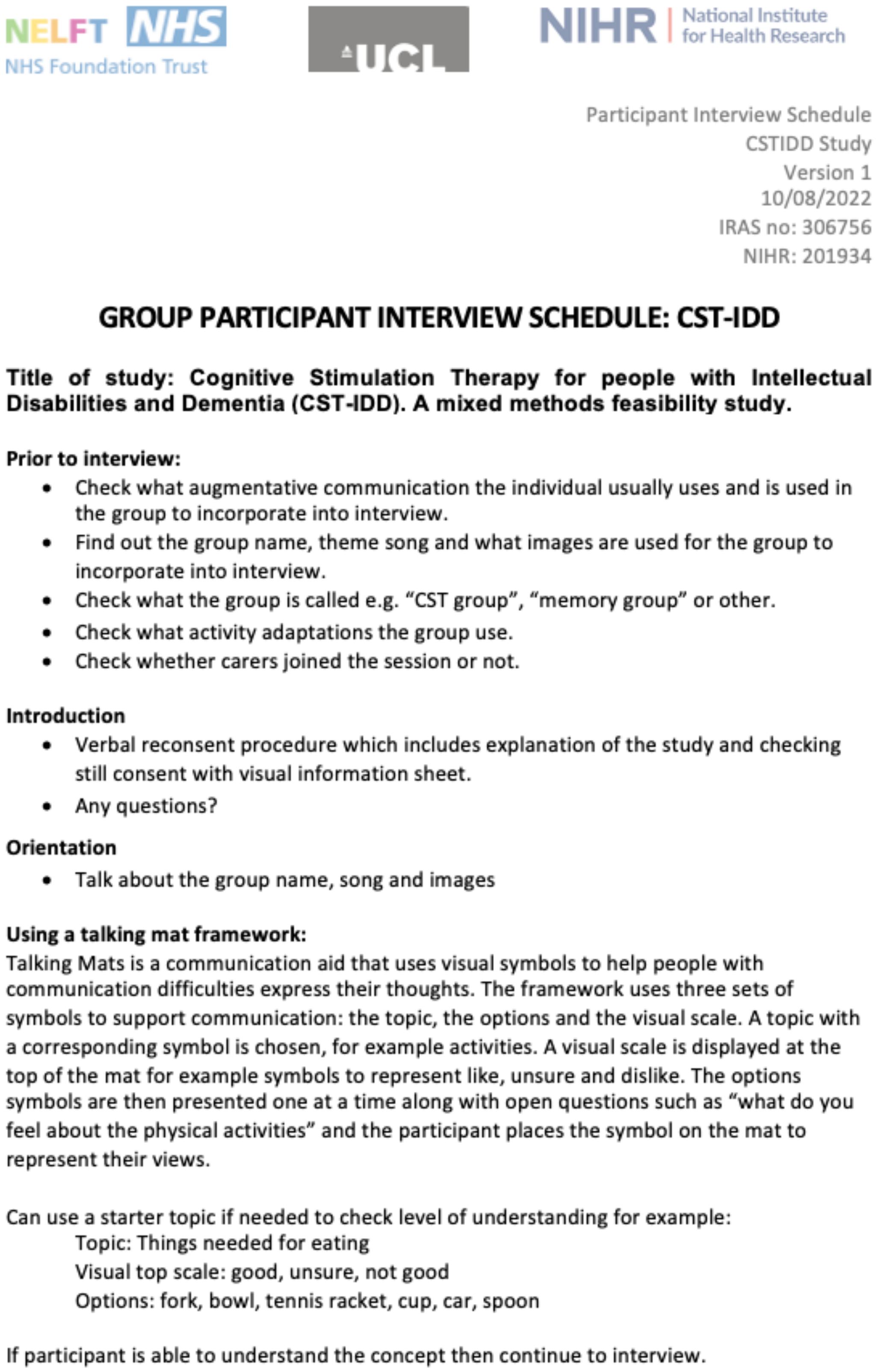
- What were your experiences of the research process for example your interaction with the research team, or information provided about the research?

Ending

- Thank you for your time and information
- Next steps: would you like a copy of the transcript to be sent to you to check?
- A copy of results will be sent to all participants, any further questions?

Appendix Q

Group Participant Interview Schedule



Participant Interview Schedule
CSTIDD Study
Version 1
10/08/2022
IRAS no: 306756
NIHR: 201934

GROUP PARTICIPANT INTERVIEW SCHEDULE: CST-IDD

Title of study: Cognitive Stimulation Therapy for people with Intellectual Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

Prior to interview:

- Check what augmentative communication the individual usually uses and is used in the group to incorporate into interview.
- Find out the group name, theme song and what images are used for the group to incorporate into interview.
- Check what the group is called e.g. "CST group", "memory group" or other.
- Check what activity adaptations the group use.
- Check whether carers joined the session or not.

Introduction

- Verbal reconsent procedure which includes explanation of the study and checking still consent with visual information sheet.
- Any questions?

Orientation

- Talk about the group name, song and images

Using a talking mat framework:

Talking Mats is a communication aid that uses visual symbols to help people with communication difficulties express their thoughts. The framework uses three sets of symbols to support communication: the topic, the options and the visual scale. A topic with a corresponding symbol is chosen, for example activities. A visual scale is displayed at the top of the mat for example symbols to represent like, unsure and dislike. The options symbols are then presented one at a time along with open questions such as "what do you feel about the physical activities" and the participant places the symbol on the mat to represent their views.

Can use a starter topic if needed to check level of understanding for example:

Topic: Things needed for eating
Visual top scale: good, unsure, not good
Options: fork, bowl, tennis racket, cup, car, spoon

If participant is able to understand the concept then continue to interview.

Topic: The group (use the name and symbol used for the group)

- Visual top scale: Like, unsure, dislike
- Options:
    - Session content - use the symbol used for the activity or one symbolising the activity that was done. Use one card/symbol for each activity done that day.
        - What did you feel about [the activity]?
    - Support
        - What did you feel about the support from [the group facilitators]?
        - What did you feel about the involvement of [your carer]?
    - Group format
        - What did you feel about doing the group with other people?
        - What did you feel about the length of the session?
        - What do you feel about joining the groups twice a week?
    - Offer blank tiles to fill in:
        - Is there anything else you would like to say about the group that is missing from this mat?

Topic: The research

- Visual top scale: Like, unsure, dislike
- Options:
    - Questionnaires
        - How did you find doing the questionnaires?
    - Information given
        - How did you find the information that you have been given about the research?
    - Research team
        - How did you find contact with the researchers doing the questionnaires?
    - Offer blank tiles to fill in:
        - Is there anything else you would like to say about the research that is missing from this mat?

Future

- If the group was to run again would you like there to be any changes?

Ending

- Thank you for your time and information
- Next steps: would you like a copy of the talking mat pictures to look back on?
- A copy of results will be sent to all participants, any further questions?

Appendix R

Talking Mat Images – full copy redacted due to copyright

Below are the images used for the starter mat

Below are the Photosymbols and PECS options for the main Talking Mat™ interview

Appendix S

CSTIDD Supplement – full copy redacted due to copyright

Making a
difference *1*
SECOND EDITION

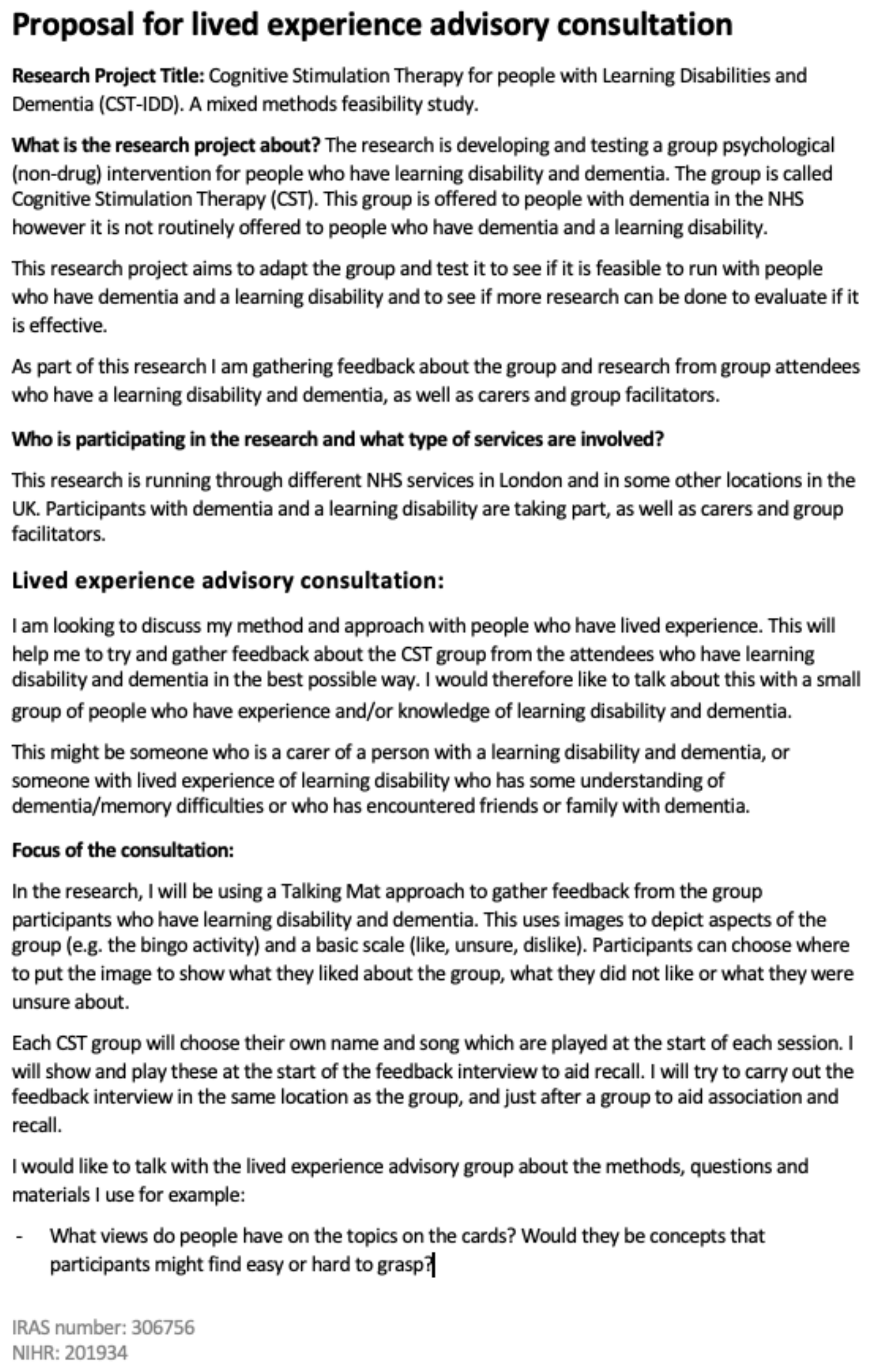
Group Cognitive Stimulation Therapy

Adaptations for People With Learning Disabilities
A supplement for facilitators

Appendix T

Proposal for Lived Experience Consultation on Talking Mat Methodology

The below document was sent to professional stakeholders to explain the project and proposed consultation.



Proposal for lived experience advisory consultation

Research Project Title: Cognitive Stimulation Therapy for people with Learning Disabilities and Dementia (CST-IDD). A mixed methods feasibility study.

What is the research project about? The research is developing and testing a group psychological (non-drug) intervention for people who have learning disability and dementia. The group is called Cognitive Stimulation Therapy (CST). This group is offered to people with dementia in the NHS however it is not routinely offered to people who have dementia and a learning disability.

This research project aims to adapt the group and test it to see if it is feasible to run with people who have dementia and a learning disability and to see if more research can be done to evaluate if it is effective.

As part of this research I am gathering feedback about the group and research from group attendees who have a learning disability and dementia, as well as carers and group facilitators.

Who is participating in the research and what type of services are involved?

This research is running through different NHS services in London and in some other locations in the UK. Participants with dementia and a learning disability are taking part, as well as carers and group facilitators.

Lived experience advisory consultation:

I am looking to discuss my method and approach with people who have lived experience. This will help me to try and gather feedback about the CST group from the attendees who have learning disability and dementia in the best possible way. I would therefore like to talk about this with a small group of people who have experience and/or knowledge of learning disability and dementia.

This might be someone who is a carer of a person with a learning disability and dementia, or someone with lived experience of learning disability who has some understanding of dementia/memory difficulties or who has encountered friends or family with dementia.

Focus of the consultation:

In the research, I will be using a Talking Mat approach to gather feedback from the group participants who have learning disability and dementia. This uses images to depict aspects of the group (e.g. the bingo activity) and a basic scale (like, unsure, dislike). Participants can choose where to put the image to show what they liked about the group, what they did not like or what they were unsure about.

Each CST group will choose their own name and song which are played at the start of each session. I will show and play these at the start of the feedback interview to aid recall. I will try to carry out the feedback interview in the same location as the group, and just after a group to aid association and recall.

I would like to talk with the lived experience advisory group about the methods, questions and materials I use for example:

- What views do people have on the topics on the cards? Would they be concepts that participants might find easy or hard to grasp?

IRAS number: 306756
NIHR: 201934

- What views do people have on the use of photographic images and symbols/line drawings? Are they intuitive/easy to understand or not?
- What views do people have on the size of the cards? Are the pictures/text easy to see?
- (Optional depending on the group) What views do people have about doing a test run? (Usually when doing a Talking Mat, you might do a test run e.g. ask people to categorise images like fork, cup, car, shoe as things you use for eating or things you don't use for eating. This helps you to see if they understand how to do the Talking Mat. The difficulty in doing so is that it can be hard for people with dementia to shift category. So, it might be hard for people to move from categorizing things you need for eating, to things they liked or did not like about the group. However, without doing a test run, we don't know if the method is understood.)
- (Optional depending on the group) I am aware that it might be hard for participants to remember the group and understand what we are talking about. I listed some ideas to help association and recall above, what views do people have on this? What other ways have people found that help recall?

Example focus group plan:

This is just a rough idea of what I thought might be helpful to include in a focus group which is very flexible.

Welcome and introductions:

Joanna introduce name and role and group introduce themselves

Overview of the session:

Timing of the session, any practical things to note

Background information about focus of the session *(with easy read)*

Ground rules/session guidelines:

To discuss how best to do this (easy read)

Confidentiality, respecting each other's opinions and experiences, no right or wrong answers, no question is compulsory to answer, can ask questions at any point, can take breaks, taking notes but anonymous and a summary of main points discussed, summary can be shared after to check for accuracy, anything else?

Themes and questions for discussion:

Views on the topics / Views on the images / Views on the cards /Views on the test run / Views on recall

Any other comments?

End:

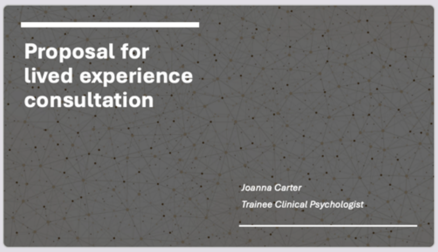
Summarize key themes from the discussion / reflections on what discussed

Thank people for their time and contribution

Explaining next steps: Check if people want a summary and how, confirm payment for time, recap on how information from the group will be used.

Signpost support if needed

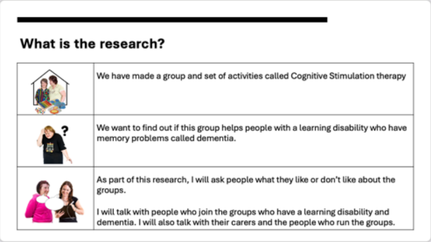
The below presentation was used to introduce the topic and the proposed consultation to the UK steering group for intellectual disabilities and dementia. Professionals and experts by experience were present in the meeting.



Proposal for lived experience consultation

Joanna Carter

Trainee Clinical Psychologist



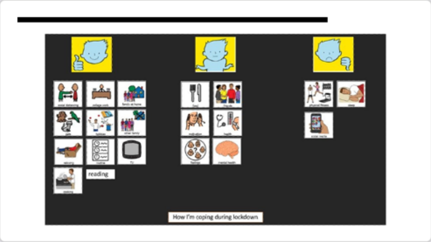
What is the research?

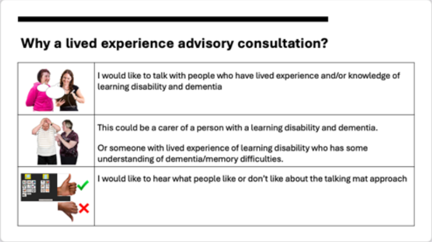
We have made a group and set of activities called Cognitive Stimulation therapy

We want to find out if this group helps people with a learning disability who have memory problems called dementia.

As part of this research, I will ask people what they like or don't like about the groups.

I will talk with people who join the groups who have a learning disability and dementia. I will also talk with their carers and the people who run the groups.





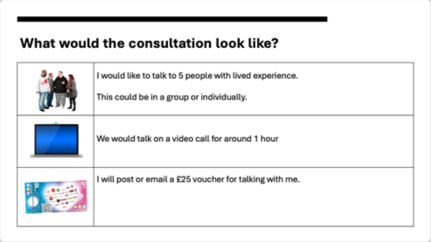
Why a lived experience advisory consultation?

I would like to talk with people who have lived experience and/or knowledge of learning disability and dementia

This could be a carer of a person with a learning disability and dementia.

Or someone with lived experience of learning disability who has some understanding of dementia/memory difficulties.

I would like to hear what people like or don't like about the talking mat approach



What would the consultation look like?

I would like to talk to 5 people with lived experience.

This could be in a group or individually.

We would talk on a video call for around 1 hour

I will post or email a £25 voucher for talking with me.

Any Questions?