

Background

- Cognitive Stimulation Therapy (CST)** is an evidence-based, cost-effective group intervention for mild-moderate dementia
- Recommended in **UK National Institute for Health and Care Excellence (NICE) guidelines** to support cognition, independence, and well-being
- CST is associated with cognitive, psychosocial, and relational benefits
- Implemented in **43 countries**, including routine use in UK NHS memory services
- Virtual CST was developed in response to COVID-19 disruptions to face-to-face CST and has primarily been evaluated in common dementias

Rare dementias	Key clinical challenges
Primary Progressive Aphasia (PPA)	Speech, language, and communication
Posterior Cortical Atrophy (PCA)	Visual processing and visuospatial skills
Behavioural Variant Frontotemporal Dementia (bvFTD)	Personality, behaviour, and social functioning

Why adapt CST for rare dementias?

Unmet need: Rare dementias are often younger onset, with high psychosocial impact and limited tailored support

Evidence gap: CST is well-evidenced in common dementias, but evidence in rare dementias remains limited

Virtual opportunity: Existing virtual CST provides a feasible foundation for rare dementia-specific adaptation and improved access for geographically dispersed groups

Methods

Phase 1: Adaptation of virtual CST for PPA, PCA, bvFTD

- Integrated evidence from CST and rare dementia psychosocial intervention literature
- Consulted **9 rare dementia specialists** and **2 Patient and Public Involvement leads**; conducted **10 structured focus groups** with **10 people with rare dementias** and **8 care partners** across three stages: introduction, feedback/adaptation, and taster evaluation

Phase 2: Feasibility and acceptability study

Single-arm, mixed-methods feasibility study: **14 virtual** CST sessions delivered **twice weekly** over **7 weeks**

Feasibility criteria

Feasibility is assessed using pre-specified progression criteria:

Recruitment	20 participants per group by March 2027
Adherence	Proportion of participants attending $\geq 75\%$ of sessions
Retention	Proportion of participants completing follow-up measures
Acceptability	Qualitative interviews

Note. Go / Review / Stop thresholds for adherence and retention: $\geq 75\%$ / 45–74% / $< 45\%$

Baseline and follow-up measures

- Health resource use, cognition, quality of life, engagement, and independence assessed using a combination of bespoke and standardised measures

Results

Phase 1: Adaptation of virtual CST for PPA, PCA, bvFTD

Adaptation focused on two domains tailored to PPA, PCA, and bvFTD presentations:

- Content:** person-centred, age-appropriate activities and cognitive accessibility
- Virtual delivery:** technical accessibility, remote facilitation, and online group interaction

Example adaptation from the “Being Creative” session

- Original virtual CST activity:** Paper cutting
- Challenge:** High visual-motor and safety demands, particularly for people with PCA. Focus groups highlighted the need for **culturally meaningful, age-appropriate**, and **cognitively accessible** creative activities across rare dementia presentations

3. Rare dementia-specific adaptations:

- Artwork exploration:** Screen-based artwork explored through prompts eliciting **sensory associations** and **creative** responses, e.g., “If you stepped into the painting, what might you see, hear, smell, or sense?” and “What would you change?”



Edward Hopper, Automat (1927). Des Moines Art Center. Public domain.

- Create your own mystery:** Group builds a humorous mystery narrative around a missing item

Note. Activities were **flexibly tailored to group preferences** and PPA, PCA, and bvFTD presentations, with visual, language, and social-interaction elements adjusted to support participation

Results

Phase 2: Feasibility and acceptability study

Table 1. Preliminary feasibility outcomes against progression criteria

Group	n recruited	Adherence	Retention (HRU)	Retention (Other)
PCA	22	77%	95%	95%
PPA	12	100%	100%	100%
bvFTD	9	89%	100%	89%

Note. All available adherence/retention outcomes meet **Go** thresholds ($\geq 75\%$). PCA recruitment complete; PPA and bvFTD ongoing. HRU = health resource use; Other = cognition, quality of life, engagement, and independence

Qualitative interviews to date: people with PPA, PCA, and bvFTD (n=27); care partners (n=15)



CONFIDENCE & COMMUNICATION

“I am more willing to speak.”

PWD (PPA)



GROWTH & CHALLENGE

“I think that it's made me realize you've got to keep challenging yourself...you might not be able to do it that way, but you can try and do it this way”

PWD (PCA)



CONNECTION & BELONGING

“These sessions have been absolutely brilliant...the opportunity to have discussion about current news stories with people who listen, the banter and the topics will be unfortunately, far outside many peoples remit in their daily lives... it is also beneficial to be part of an informal group where everyone can be themselves.”

PWD (PCA)



IMPACT BEYOND SESSIONS

“She's now decided to take [REDACTED] out for once a week, or once every two weeks...for a drink, and they play UNO together...I think she heard how [REDACTED] was talking and engaged [IN THE CST SESSIONS], and thought that it'd be really good...to actually go out”

Care Partner (bvFTD)

Key Message

- Findings to date suggest that adapted virtual CST is feasible and acceptable for people with PPA, PCA, and bvFTD, and may address an unmet care need
- High adherence and retention following targeted content and virtual delivery adaptations support further evaluation