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The Comprehensive Resilience-building psychosocial Intervention (CREST) for people with dementia in the community: a feasibility and acceptability study

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Abstract

Background A dementia diagnosis can lead to a decline in cognitive, social, and physical health, but people with dementia can live meaningful lives and participate actively in society with psychosocial support. This single-arm, non-randomised feasibility study explored the feasibility and acceptability of a Comprehensive *RE*silience-building psychoSocial intervenTion (CREST) for people with dementia, their caregivers, General Practitioners (GPs), and the public.

Methods Nine people with dementia and their primary caregivers living in the community ($n=9$ dyads) completed the CREST intervention which had three components (cognitive stimulation therapy [CST], physical exercise, and dementia education). Quantitative secondary outcomes were assessed at baseline and following the 15-week intervention; qualitative interviews were conducted during and post-intervention. All study components were assessed against pre-defined criteria, to determine the feasibility of conducting a future definitive trial.

Results Recruitment of people with dementia and their caregiver was a significant challenge and led to considerable delays to the onset and conduct of the intervention. Only 13% of eligible GP practices agreed to assist in recruitment and achieved a 6% enrolment rate; a community-based recruitment strategy proved more effective, yielding a 29% enrolment rate. However, once recruited, participants maintained high attendance and adherence to the content of each component with average adherence rates of 98% for CST, exercise sessions and caregiver education. Adherence to secondary exercise measures was lower, with home exercise diary completion at 37% and Fitbit wear adherence at 80% during the day and 67% at night. The people with dementia felt their concentration and fitness had improved over the 15-week intervention and particularly enjoyed the social aspects (e.g. group classes, exercising with partners from the community). Caregivers felt they had better knowledge and understanding following their education component and reported that the social aspects (interacting and sharing experiences with each other) were important. Overall, participants reported that the three components of the intervention were feasible and acceptable. In addition, the quantitative measures and health economic tools employed were feasible. However,

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the secondary elements of the exercise component (recording home exercise diaries and Fitbit use) were not considered feasible. Overall, pre-defined criteria for progression to a definitive intervention were fulfilled in terms of acceptability, retention and fidelity but not recruitment.

Conclusion While overall, the CREST intervention was feasible and acceptable to participants, significant difficulties with recruitment of people with dementia and their caregiver through GP practices impacted the viability of delivering the intervention. Recruitment through community-based groups proved a more feasible option and further work is needed to overcome barriers to recruiting this cohort before a larger-scale trial can be conducted.

Trial registration ISRCTN25294519.

Keywords Dementia, Psychosocial intervention, CST, Exercise, Education

Background

Dementia is an umbrella term for several diseases which progressively affect memory, cognitive abilities and behaviour, and impact a person's ability to maintain the activities of daily living [1]. Globally, there are more than 50 million people living with dementia, and it is estimated that dementia will impact over 150 million people worldwide by 2050 [2]. Almost 9.9 million people develop dementia annually, and by 2030, it is estimated that the cost of caring for people with dementia worldwide will rise to US\$2 trillion, presenting a significant global health and societal challenge [1]. In Ireland, there are an estimated 65,000 people living with memory problems or dementia and upwards of 60% remain living in the community after diagnosis supported by informal caregivers such as family members or close friends [3]. It may be possible for people with dementia to continue living a meaningful life and actively participating in society, provided a supportive psychosocial environment is available [3–6].

Resilience is a dynamic process of “negotiating, adapting to, or managing significant sources of stress or trauma” [7]. Positive adaptations focus on strengthening modifiable intrapersonal skills and protective factors to enable the person to remain psychologically, socially, and physically healthy in the face of adverse experiences [8]. In the context of dementia, resilience-building strategies need to be multidimensional, and must target family and community, in addition to strengthening the person with dementia's own intrapersonal assets and protective factors [9–12].

A review of research identified a number of components that are important to resilience building for people with dementia: cognitive stimulation, exercise, social connectedness and education. A systematic review on the effectiveness of psychosocial interventions for people with dementia found that cognitive stimulation therapy and physical exercise were particularly beneficial [13]. Moreover, group-based exercises with a strong social element have been found to promote social connectedness [13–16]. Additionally,

dementia education targeted at informal caregivers, general practitioners (GPs) and the wider community can build resilience in people with dementia by strengthening the support structures around them and reducing stigma [17–19]. Despite there being research around psychosocial interventions and dementia, gaps remain. Many interventions do not simultaneously address multiple dimensions of dementia care, such as cognitive, emotional and physical health [20].

Against this background, the novel Comprehensive REsilience-building psychoSocial intervenTion (CREST) was developed to create a supportive psychosocial environment for people with dementia living in the community [21]. The CREST intervention was delivered over 15 weeks, in five separate but interrelated programmes (Fig. 1):

- (1) The ‘Making a difference’ Cognitive Stimulation Therapy (CST) programme for people with dementia developed by Spector et al. [22] (7 weeks);
- (2) Exercise programme for people with dementia (8 weeks) based on a modified version of the PRINCE structured exercise programme [23];
- (3) Educational programme for carers (6 weeks) based on the DARES structured education programme [24] modified to meet the needs of informal caregivers of people with dementia and informed by the Alzheimer Society of Ireland's Family Carer Training programme [25];
- (4) A dementia awareness programme for the general public/community (once-off) based on the Irish Health Service Executive's *Dementia: Understand Together* campaign [26];
- (5) A dementia education workshop programme for local GPs (once-off) developed by the PREPARED team (Primary Care Education, Pathways and Research of Dementia).

The intervention has been described in detail in a previous publication [21]. We designed a study to examine the

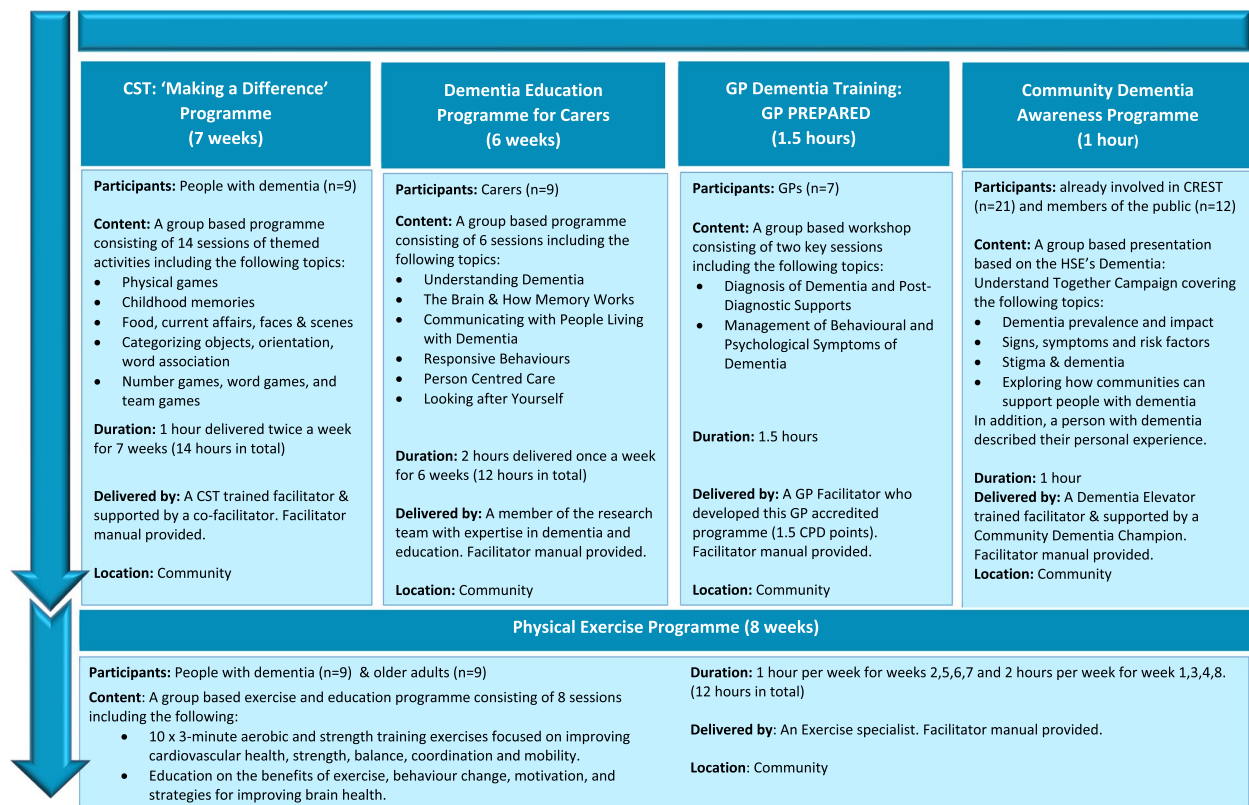


Fig. 1 Overview of the CREST Intervention

feasibility and acceptability of the CREST intervention for participants; and to test the feasibility and acceptability of a proposed future definitive trial.

Methods

The non-randomised feasibility study was registered (ISRCTN25294519) and a detailed protocol published [21]. Any deviations from the protocol will be highlighted in the relevant sections below. Here, we briefly summarise the methods.

Study design and setting

A single-arm, non-randomised design was chosen for this feasibility study to focus on assessing the practicality of implementing the intervention and identifying potential issues before progressing to a full-scale trial. This design allows for efficient use of resources while gathering crucial data on acceptability and potential effectiveness, which will inform future randomised controlled trials.

The general hypothesis of the study was that the CREST intervention was feasible and acceptable to participants (people with dementia and their caregivers) and key stakeholders, demonstrating the potential for successful recruitment, adherence, and data collection. The

study was conducted in the West of Ireland from February 2019 to March 2020. Pre-defined criteria, as outlined in the study protocol [21] were used to determine the acceptability and feasibility of the CREST intervention and whether it could progress to a future definitive randomised controlled trial (RCT). One change was made to the feasibility objectives which differed to that published in the protocol. Feasibility objective 9 considered baseline score and variability of 'primary outcome measures' and not 'secondary outcome measures' as originally planned. In addition, the criteria for progressing to a future definitive randomised controlled trial for this objective did not include 'variability of secondary outcomes to fall within acceptable parameters, when calculating sample size and possible attrition' as originally outlined in the protocol. The criteria for progressing to a definitive trial were matched against CREST feasibility objectives (Table 1), and progression to an RCT was based on achieving all the criteria.

Facilitators and co-facilitators of the intervention

The CREST intervention was delivered by facilitators with expertise in the respective components, supported by co-facilitators (a study research assistant and

Table 1 Feasibility objectives

#	CREST Feasibility objectives	Criteria for proceeding to a future definitive randomised controlled trial
1	Number of participants (people with dementia and caregivers) who are screened, judged eligible and agree to take part in the study	30% of eligible participants (people with dementia & caregivers) can be recruited
2	Identification of optimal strategy for recruitment of participants for future definitive trial	Optimal recruitment strategy identified, informed by recruitment rates and qualitative data from key stakeholders
3	Identification of barriers and enablers to stigma change in dementia	A list of barriers and enablers to stigma change in dementia to be generated from the analysis of qualitative data from key stakeholders
4	Willingness of key gatekeepers (i.e. GPs, local Alzheimer Cafés, Western Alzheimer's groups) to recruit participants	> 60% of key gatekeepers approached are willing to support the recruitment of participants
5	Feasibility and acceptability of the intervention content, delivery, and fidelity assessments	> 70% of participants attend \geq 60% of intervention sessions. The intervention is delivered in line with feasibility and fidelity targets (i.e. content, frequency, and quality of the programmes are in line with the programme manuals)
6	Follow-up rates, outcome completion and adherence or compliance rates	< 20% of participants lost to follow-up \geq 50% of people with dementia and caregivers adhere to the intervention > 70% wear rate for Fitbit smart wearables by people with dementia
7	Reasons for non-recruitment, non-adherence, or attrition	A list of the reasons for non-recruitment, non-adherence, or attrition data generated from the data obtained from participants
8	Acceptability of the recruitment process, assessments, data collection tools, intervention content and delivery to participants	Recruitment processes, assessment, data collection tools, intervention content and delivery perceived as acceptable by > 70% of participants (people with dementia and caregivers)
9	Baseline score and variability of primary outcome measures among participants to inform sample size estimates for a future definitive trial ^a	Sample size estimates for required number of persons with dementia can be calculated, from baseline scores on the primary outcome measure of quality-of-life in people with Alzheimer's disease (the QoL-AD)
10	Evaluation of cost analyses process	Economic data can be collected to inform the design of the economic component of any future trial

^a This differed to the original protocol and is described in the paragraph above

a psychology student). Delivery of each intervention component was guided by a facilitator manual. In addition, all facilitators and co-facilitators attended a 4.5-h bespoke training session to prepare them to deliver the intervention.

Inclusion of participants

Recruitment of people with dementia and their primary caregiver (dyads) was initially planned to be undertaken in GP practices [21]; however, this strategy did not yield many participants. An alternative community-based recruitment strategy was employed [21], centering on local dementia support and advocacy groups and networks (e.g. The Alzheimer's Society of Ireland, Western Alzheimer's). The inclusion criteria for the people with dementia included adults >60 years of age, living in the community with either a formal diagnosis of mild to moderate dementia; or prescribed dementia medications; or their GP believed the person had memory problems and the person had a provisional diagnosis of dementia based on the DSM-IV criteria. They were also required to have their primary caregiver agree to participate in aspects of the CREST intervention. Further information about the demographic characteristics of the participants in CREST are described in the results.

Sample size

A formal sample size calculation was not required for this feasibility study, given the study design [27]. A purposive sample of 10 dyads (people with dementia and their primary caregiver) was considered appropriate to provide data to explore the feasibility objectives and acceptability.

Data collection and procedure

Quantitative data

A range of outcome measurements were collected pre- and post-intervention as described in the protocol [21] and are listed in Table 2. Participants were asked to rate ease of completion for each measurement tool on a 5-point scale (1: very easy; 5: very difficult), with space for comments. The time taken to complete each measure was also recorded by a researcher. Demographic details were collected on all study participants. Additional quantitative data was also collected for each component of the CREST intervention programme (Table 2.). These are described in further detail below.

Qualitative data

The qualitative descriptive approach [40] has been described in detail elsewhere [21]. Semi-structured interviews using interview guides were used to collect the data and were reviewed by one person with dementia, and one caregiver, from the study advisory board to ensure

suitability. All interviews were audio-recorded and transcribed verbatim. During the intervention, all people with dementia took part in two group interviews (week 4 of the CST component; week 5 of the exercise component) and all caregivers took part in one group interview (week 4 of the caregiver education component). These group interviews were 30–45 min in duration. Post-intervention (weeks 16–19) individual face-to-face interviews were conducted with people with dementia (20–40 min long) and caregivers (40–60 min) either in the intervention venue or in their homes. Facilitators ($n=5$) and co-facilitators ($n=2$) (30–45 min long), and participating GP and practice staff ($n=4$: 2 GPs, 1 Practice Manager, 1 Nurse) (15–20 min long) were also interviewed post-intervention, either face to face or by telephone. Finally, a 1-h face-to-face group interview was held with the older adults post-intervention.

Intervention fidelity and adherence

The co-facilitators completed a fidelity form to assess whether elements of both the CST and exercise components were delivered as intended. Adherence to the intervention was assessed through the facilitators and co-facilitators completing an adherence to intervention delivery and feedback form after each session of each of the components of the intervention (examples in Additional file 1). Likewise, people with dementia and their caregivers completed a simplified version of this adherence form (Additional file 2).

The co-facilitators of the CST component also completed a Participant Monitoring Progress form from the 'Making a Difference' manual [22] using a 5-point scale (1: low; 5: high), with space for comments. This assessed the engagement of the people with dementia with the programme in terms of interest, communication, enjoyment, and mood.

Health economic assessment

A preliminary health economic assessment was conducted to evaluate the cost analyses process, to estimate the cost of the intervention and to explore the estimation of healthcare costs and quality-adjusted life years (QALYs). Intervention costs included expenditure on patient recruitment (e.g. travel costs, postage), overheads (venue hire, equipment), and staff training and facilitation. Other healthcare service use was captured via a questionnaire (Resource Utilisation in Dementia-lite version (RUD-lite) [39] completed by the caregivers. Resource use was captured at baseline and post-intervention for a period of 15 weeks. Additionally, caregivers estimated the travel and private expenses associated with the daily management of dementia (e.g. hospital or GP attendances, prescription costs, fuel costs), and

Table 2. Data completion at each time point

	People with dementia	Caregivers	Older adults	Facilitators	Co-facilitators	Community dementia event attendees	GP PREPARED event attendees	GPs and practice staff involved in recruitment
PRE-INTERVENTION (Feb – Oct 2019)								
	Consent form	✓	✓	✓	✓		*✓	✓
	Demographics questionnaire	✓	✓	✓	✓	*✓	*✓	✓
	QoL-AD [28]	✓						
	MMSE [29]	✓						
	GDS[30]	✓						
	SIS [31]	✓						
	PPOM [32]	✓						
	EQ-5D-5L [33]	✓						
	Recruitment process feasibility questionnaire	✓						
	DK-20 [34]	✓	✓					
	DAS [35]		✓					
	ZBI [36]	✓						
	SSCQ [37]	✓						
	AC-QoL [38]	✓						
	RUD-lite (baseline: RUD-B) [39]	✓						
INTERVENTION (16 Oct 2019 – 7 Feb 2020)								
CST component (7 weeks)	Attendance sheet – every session			✓	✓			
	CST - Participant Monitoring Progress form as per manual – every session				✓			
	Facilitator fidelity form – every session					✓		
	Session adherence (group verbal feedback) – every session	✓						
	Adherence to intervention delivery & feedback form – every session				✓	✓		
	Process interview – week 4 of component	✓						

Table 2. (continued)

	People with dementia	Caregivers	Older adults	Facilitators	Co-facilitators	Community dementia event attendees	GP PREPARED event attendees	GPs and practice staff involved in recruitment
POST-INTERVENTION (8 Feb 2020 – 31 Mar 2020)								
QoL-AD [28]	✓							
MMSE [29]	✓							
GDS [30]	✓							
SIS [31]	✓							
PPOM [32]	✓							
EQ-5D-5L [33]	✓							
DK-20 [34]		✓	✓					
DAS [35]			✓					
ZBI [36]		✓						
SSCQ [37]		✓						
AC-QoL [38]		✓						
RUD-lite (follow-up: RUD-F) [39] (incl. Travel and Private Expenses form)		✓						
Exercise form (people with dementia) exercise habits prior to and during CREST)		✓						
Post-intervention interviews	✓	✓	✓	✓	✓			✓

with participating in the CREST intervention (e.g. buying sports footwear for the Exercise component). A vector of unit costs was applied to calculate the cost associated with each resource activity (Additional file 3). QALYs were estimated based on European Quality of Life (EuroQoL) 5 Dimension scale (EQ-5D-5L) instrument responses completed by the people with dementia [33]. In order to assess the appropriateness and acceptability of the health economic data collection instruments, the people with dementia and caregivers were asked to rate how easy/difficult it was to complete them and they were also asked about them in the qualitative interviews.

Social marketing evaluation

Social marketing was used to gain a better understanding of stigma in relation to dementia in Ireland and identify possible means to enact stigma change. Potential barriers or enablers to stigma change were extracted from existing literature on stigma in dementia, from interviews with

each person with dementia, caregivers and older adults who supported the people with dementia in the exercise programme, and from secondary outcomes [31, 35].

Data analyses

Quantitative analysis

Quantitative secondary outcome measurement data was quality-checked by two members of the research team. The original protocol [21] stated that all study questionnaires would be inputted into SPSS data builder to create a project database but instead, the data were manually entered into a Microsoft Access database developed for CREST, containing tailored entry forms for each outcome measure. The database automatically calculated scores upon data entry, providing a third quality-check. Data were then exported to Microsoft Excel and analysed in R v3.6.3 (R, Vienna, Austria). Suitable summary statistics for baseline, post-intervention and change scores were calculated. Attendance and adherence calculations were summarised as a percentage of the total possible

score (e.g. attendance at 7/8 sessions was calculated as 87.5% attendance). No formal analyses were carried out, as this would be prone to type II errors given the small sample size used for assessing feasibility.

Qualitative analysis

All qualitative interviews were transcribed verbatim and anonymised. Each respective data set was analysed and coded using directed qualitative content analysis, focusing on the relevance of the data to the research aims and grouping them into themes [41]. Each individual data set was initially coded independently and the codes were then checked by a second member of the qualitative team (DC, SS, PD, GOS). Peer debriefing throughout the analysis process with the research team helped to clarify and resolve any coding issues. Any discrepancies were discussed and resolved. The criteria outlined by Lincoln and Guba were used to ensure rigour [42]. NVivo 12.0 (QSR International, Melbourne, Australia) was used to facilitate the analysis. A more detailed outline of the qualitative interviews and findings will be presented in a separate publication.

Health economic assessment analysis

EQ-5D-5L responses were transformed using an algorithm into a single health state index score, based on values elicited via the time trade-off and discrete choice approach for the Irish population [43]. EQ-5D-5L scores at baseline and follow-up were used to calculate participant-specific QALYs gained over 15 weeks using the area under the curve method [44]. Total healthcare costs and QALYs were estimated for the time period of the 15-week duration of the CREST study.

Social marketing analysis

Using collective intelligence systems methodology, the statements, identified as potential barriers or enablers to stigma change, were clarified by a multidisciplinary group of three researchers led by a Social Marketing expert (CD). In brief, the text of each statement was confirmed by majority agreement in the group and statements were categorised as either a 'barrier' or 'enabler' to stigma change. Duplicated statements (i.e. those identically phrased) were then removed. If statements were similar but had clarifying text to distinguish them (e.g. 'Lack of education' versus 'Lack of education in young people'), both statements were retained. The final list of unique 'barrier' or 'enabler' statements was then re-examined, to identify the societal levels in which stigma related to dementia was evident (i.e. individual, family, community,

or structural), and to highlight any factors which may already be in operation to effect positive change.

Results

Although this was a non-randomised feasibility study, our findings are reported in line with the CONSORT extension to pilot and feasibility trials [45]; the completed CONSORT checklist is available in Additional file 4.

Participant characteristics

People with dementia and caregivers

Ten dyads were recruited; however, one dyad withdrew after the first week due to illness, and so nine dyads received the CREST intervention. Recruitment of the participants is described in detail below. There were five male and four female people with dementia with a mean age of 76 years. Baseline Mini-Mental State Exam (MMSE) scores [29] indicated mild to moderate-stage dementia ($M=20.40$, $SD=4.90$), and the majority (79%) reported having memory problems for fewer than 4 years. The majority of caregivers were female with a mean age of 57.9 years. Most caregivers were the spouse of the person with dementia and lived with the person they cared for. Further demographic details are presented in Table 3.

Older adults

A total of nine older adult volunteers (male $n=5$; female $n=4$) joined the CREST exercise programme, to provide support and encouragement to the people with dementia during the exercise component of the intervention. These participants were aged between 60–69 years ($n=4$), 70–79 years ($n=4$) and >80 years ($n=1$). They all had completed secondary-level education or above. Only one older adult ($n=1$) had previously undergone training on dementia, in the form of in-person training. Conversely, the majority of the older adults had previous experience of interacting with people with dementia ($n=7$): these experiences were either with a relative ($n=4$) or a member of the public ($n=3$). The older adult group were typically in good health, with the majority reporting no major health issues ($n=8$), and one older adult reporting high blood pressure ($n=1$).

Community dementia awareness programme participants

A total of 33 people attended the programme, 21 of whom were already participating in CREST (people with dementia ($n=6$), their caregivers ($n=8$) or older adults ($n=7$)). Twelve therefore had no previous involvement; the majority were female ($n=7$) and participants ranged in age from 30 to 70+ years of age, with almost half aged 60–69 years ($n=5$). Many indicated multiple reasons

Table 3 Demographic overview of the people with dementia and their caregiver

		People with dementia (<i>n</i> = 9)	Caregivers (<i>n</i> = 9)
Mini-Mental State Exam (MMSE) score	Mean score	20.40 (SD = 4.90)	-
Sex	Female	4	8
	Male	5	1
Age	30–39	-	1
	40–49	-	2
	50–59	-	3
	60–69	3	2
	70–79	4	1
	80–89	2	0
	Mean age	76 years (SD = 7.81)	57.9 years (SD = 12.89)
	Dyad relationship	Parent/child	4
	Spouses	5	
Time giving/ receiving care	0–4 years	7	
	5–9 years	1	
	(Missing)	1	
Living arrangement	Own home	1	-
	Living with caregiver	8	-
Education attained	Primary level	1	1
	Secondary level	4	1
	Third level	3	5
	Other (e.g. professional)	1	2
Employment status	Employed	0	3
	Homemaker	1	1
	Unemployed	0	1
	Retired	8	4

for choosing to attend, with the most frequent reasons being ‘caring for a person with memory problems/dementia’ (*n* = 4), or ‘knowing someone with memory problems/dementia’ (*n* = 9). Almost half of attendees further specified having an ‘interest in the area of dementia’ (*n* = 5). Two attendees indicated that they themselves had dementia. Most of the attendees had heard about the event through email invitations (*n* = 3) or social media (*n* = 3), while other attendees had learned of the event through posters (*n* = 2) and leaflets (*n* = 1).

GP PREPARED programme participants

Seven GPs from three different GP practices took part in the programme. All the GPs worked in GP practices attended by the people with dementia who were participating in CREST. Most participants were female (*n* = 5) and under 50 years of age (*n* = 5). The majority of the GPs (*n* = 5) had been working in their current practice for

fewer than 10 years. Most of them were currently working full-time (*n* = 6), with one attendee working part-time (*n* = 1). Though all the GPs had some previous experience of people with dementia, few had completed formal dementia training (*n* = 2).

Adverse events

There were no reported adverse events by participants during the intervention. One participant dropped out due to a medical reason in the first week of the intervention, which was independent of the intervention itself.

Criteria for progression to a future definitive randomised controlled trial

The pre-defined criteria to determine progression to a future definitive RCT (Table 1) was used as a framework for reporting the qualitative and quantitative results (Table 4).

Table 4 Feasibility objectives—assessment of criteria with supporting evidence

CREST feasibility objectives	Criteria for progressing to a definitive trial	Assessment of criteria	Evidence	Criterion fulfilled?
1 Number of participants (people with dementia and caregivers) who are screened, judged eligible and agree to take part in the study	30% of eligible participants (people with dementia & caregivers) can be recruited	Recruitment records will show response rates to invitations from GP practices and community dementia organisations (number of participants approached versus recruited)	Through GP practices, 48 potential dyads were identified. 17 were contacted, and 3 dyads were enrolled (6% of eligible dyads). Through community organisations, 24 dyads were identified and contacted, and 7 dyads enrolled (29% of eligible dyads). A full-scale RCT would not be possible using this recruitment strategy	No
2 Identification of optimal strategy for recruitment of participants for future definitive trial	Optimal recruitment strategy identified, informed by recruitment rates and qualitative data from key stakeholders	Recruitment records, and post-intervention interviews or focus groups with people with dementia, caregivers, and facilitators (Transcripts were qualitatively analysed to identify suggestions for optimal recruitment into a future trial)	Low levels of recruitment through the two participating GP practices. Delays in recruitment and between approach, enrolment, and the onset of the study while alternative recruitment avenues were explored Optimal recruitment strategy (e.g. through community organisations) was identified: 7 dyads were enrolled, representing 70% of final CREST sample. However, recruitment strategies may benefit from an additional feasibility study	Yes—partially
3 Identification of barriers and enablers to stigma change in dementia	A list of barriers and enablers to stigma change in dementia to be generated from the analysis of qualitative data from key stakeholders	All CREST participants (people with dementia) caregivers, facilitators, and older adults) discussed stigma during interviews/focus groups. SIS (people with dementia) and DAS (older adults) measures were completed to indicate attitudes regarding dementia and stigma	Transcripts and secondary outcome responses were qualitatively analysed to identify and categorise the barriers and enablers to reducing stigma associated with dementia in Ireland <i>Social marketing data will be published separately</i>	Yes
4 Willingness of key gatekeepers (i.e. GPs, local Alzheimer Cafés, Western Alzheimer groups) to recruit participants	> 60% of key gatekeepers approached willing to support the recruitment of participants	Recruitment strategy records confirmed recruitment progress and identified potential gatekeeper issues (e.g. a lack of uptake by GP practices to promote the study to eligible participants)	Low uptake by GP practices (only 2 (14%) of the approached practices participated), which led to delays in recruitment, seeking alternative recruitment avenues, and time elapsing between approach, enrolment, and the onset of the study High uptake by community organisations willing to assist with recruitment (100% of approached local dementia support groups)	Yes—partially

Table 4 (continued)

CREST feasibility objectives	Criteria for progressing to a definitive trial	Assessment of criteria	Evidence	Criterion fulfilled?
1 Number of participants (people with dementia and caregivers) who are screened, judged eligible and agree to take part in the study	30% of eligible participants (people with dementia & caregivers) can be recruited	Recruitment records will show response rates to invitations from GP practices and community dementia organisations (number of participants approached versus recruited)	Through GP practices, 48 potential dyads were identified. 17 were contacted, and 3 dyads were enrolled (6% of eligible dyads). Through community organisation, 24 dyads were identified and contacted, and 7 dyads enrolled (29% of eligible dyads). A full-scale RCT would not be possible using this recruitment strategy	No
5 Feasibility and acceptability of the intervention content, delivery, and fidelity assessments	> 70% of participants attend ≥ 60% of intervention sessions. The intervention is delivered in line with feasibility and fidelity targets (i.e. content, frequency, and quality of the delivered content is in line with the programme manuals)	Comments from the participants, research team and facilitators will identify whether the intervention content is accessible. Attendance rates of ≥ 60% for each component. Quality checks by facilitators of content delivery, to confirm fidelity	Attendance was high for all components (e.g. 96% CST; 79% Exercise; 91% Caregiver education) The content was rated positively by each respective group (e.g. people with dementia enjoyed the CST and exercise and some perceived improvements after attending) The delivery of the intervention (e.g. facilitators, venue, and scheduling) were feasible and acceptable Each component was delivered within fidelity targets (97–100% adherence in each). Fidelity assessment form was burdensome for co-facilitators, and suggestions made to improve it for future trials	Yes
6 Follow-up rates, outcome completion and adherence or compliance rates	< 20% of participants lost to follow up ≥ 50% of people with dementia and caregivers adhere to the intervention > 70% wear rate for Fitbit smart wearables by people with dementia	Qualitative and quantitative data from each component (e.g. questionnaires, session evaluation forms, home exercise diary, Fitbit wear)	9/10 participants (90%) completed the CREST intervention, 1 dyad lost at follow-up (10%) Completion: All measures were completed by participants at baseline and post-intervention (100%). Low levels of missing data. Difficulties with completing the DK-20 for older adults Average adherence to intervention content was high: CST: 98%; Exercise: 98%; Education (caregivers; community: GPs: 98–100% adherence Adherence to secondary exercise measures was low: home exercise diary (37%); Fitbit wear acceptable during daytime (80%) but not night-time (67%)	Yes—partially

Table 4 (continued)

CREST feasibility objectives	Criteria for progressing to a definitive trial	Assessment of criteria	Evidence	Criterion fulfilled?
1 Number of participants (people with dementia and caregivers) who are screened, judged eligible and agree to take part in the study	30% of eligible participants (people with dementia & caregivers) can be recruited	Recruitment records will show response rates to invitations from GP practices and community dementia organisations (number of participants approached versus recruited)	Through GP practices, 48 potential dyads were identified. 17 were contacted, and 3 dyads were enrolled (6% of eligible dyads). Through community organisation, 24 dyads were identified and contacted, and 7 dyads enrolled (29% of eligible dyads). A full-scale RCT would not be possible using this recruitment strategy	No
7 Reasons for non-recruitment, non-adherence or attrition	A list of the reasons for non-recruitment, non-adherence, or attrition data generated from the data obtained from participants	Participant interviews and evaluations of each component identified reasons for non-recruitment and attrition, e.g. dissatisfaction, logistical difficulties with travel concerns	Reasons identified for non-adherence (e.g. technical difficulties), and non-attendance by participants at individual sessions (e.g. illness in people with dementia or their caregiver or prior commitments such as pre-existing medical appointment and holidays)	Yes
8 Acceptability of the recruitment process, assessments, data collection tools, intervention content and delivery to participants	Recruitment processes, assessment, data collection tools, intervention content and delivery perceived as acceptable by > 70% of participants (people with dementia and caregivers)	Questionnaires, and semi-structured interviews or focus groups completed during and post-intervention with all participants (people with dementia and caregivers)	Questionnaire ratings and interviews with people with dementia and caregivers confirmed the recruitment process and level of information given was satisfactory Some measures were changed during the pilot to suit the needs of these groups (e.g. adherence feedback from people with dementia was gathered verbally instead of written comments; the rating scale on the caregiver session evaluation form was shortened); these revisions were feasible and acceptable for their needs The Fitbit data is presented in a separate publication [46]	Yes
9 Baseline score and variability of primary outcome measures among participants to inform sample size estimates for a future definitive trial	Sample size estimates for required number of people with dementia for a future trial can be calculated, from baseline scores on the primary outcome measure (QoL-AD)	Baseline scores for each measure based on parameters from their respective manuals. Variability in participant scores established by same parameters. These scores, along with attrition estimates, will inform final required sample size	Baseline scores and variability were within outlined parameters for all measures, as per the manuals Sample size estimates could be calculated. These indicated a total final sample of 210 participants (accounting for 20% attrition) would be needed for a future trial	Yes

Table 4 (continued)

CREST feasibility objectives		Criteria for progressing to a definitive trial	Assessment of criteria	Evidence	Criterion fulfilled?
1	Number of participants (people with dementia and caregivers) who are screened, judged eligible and agree to take part in the study	30% of eligible participants (people with dementia & caregivers) can be recruited	Recruitment records will show response rates to invitations from GP practices and community dementia organisations (number of participants approached versus recruited)	Through GP practices, 48 potential dyads were identified. 17 were contacted, and 3 dyads were enrolled (6% of eligible dyads). Through community organisations, 24 dyads were identified and contacted, and 7 dyads enrolled (29% of eligible dyads). A full-scale RCT would not be possible using this recruitment strategy	No
10	Evaluation of cost analyses process	Economic data can be collected to inform the design of the economic component of any future trial	Health economic data and itemised costings for component delivery (e.g. GP recruitment incentives, training costs, venue hire) were analysed to determine cost feasibility	The cost of the intervention was calculated at approximately €2922 per person with dementia. The chosen outcome measures were suitable. The analysis indicated it would be feasible to conduct a health economic evaluation alongside a definitive randomised controlled trial using these same methods	Yes

QoL-AD Quality of Life—Alzheimer’s Disease (care recipient version), SIS Stigma Impact Scale, DK-20 Dementia Knowledge-20, DAS Dementia Attitudes Scale

Recruitment—number of participants (people with dementia and caregivers) who were screened, judged eligible and agreed to take part in the study (Objective 1)

The strategy used to recruit participants has been described in detail in the study protocol [21]. Only 2 of 15 eligible GP practices consented to assist with dyad recruitment. Forty-eight dyads (people with dementia and their caregiver) were identified from the medical records of the two GP practices but only 17 agreed to be contacted by the research team. Of these, five consented to participate; however, two dyads later withdrew. After 10 weeks, three dyads enrolled into the CREST intervention (6% of dyads identified by the GP practices) (Fig. 2). A community-based recruitment strategy was then also instigated, which centred on local dementia support and advocacy groups and networks. This yielded 24 potential dyads, with nine agreeing to be contacted. After 12 weeks, seven of the 9 dyads were enrolled into the CREST intervention (29% of dyads identified through the community) (Fig. 2). The criterion for progression that 30% of eligible participants would be recruited was not met, as only 24% of eligible participants were recruited (Table 4).

Optimal recruitment strategy informed by recruitment rates and qualitative data from key stakeholders and gatekeepers (Objectives 2 and 4)

Criteria for progression were two-fold: that an optimal recruitment strategy could be identified from the feasibility study data, and that >60% of approached gatekeepers would be willing to support recruitment of participants. While only 13% ($n=2$) of eligible GP practices were willing/able to support participant recruitment, all of the local dementia support and advocacy groups contacted ($n=6$) supported participant recruitment to the study (Fig. 2). There was consensus among the two GP practices that did take part about how time consuming it was to identify eligible participants and that this may have presented a barrier in preventing other practices from engaging. All practice staff felt that recruitment was sometimes hindered by the inclusion criteria for eligible participants, particularly in relation to the carer's involvement. Some noted for example that some of the people with dementia they identified did not have a primary carer, while others had carers with other work or family commitments, thus making it difficult for carers to commit to the study, and preventing people with dementia from taking part. In addition, the perceived stigma and "fear" that someone they know would learn they had dementia was also considered a barrier to recruiting participants.

"Some of them too are embarrassed ... they have enough insight to know they have this and so they don't want other people knowing and they try to cover it up ..." (GP 2)

The results suggest that the criteria for progression were partially met (Table 4). While the number of GP practices who agreed to participate fell below target, community-based recruitment was identified as an acceptable alternative.

Identification of barriers and enablers to stigma change in dementia (Objective 3)

In total, 121 statements were identified through the social marketing analysis (79 barriers to stigma change and 42 enablers). The 79 barrier statements were identified at every level of society: individual, family, community, and structural level. In particular two barriers were considered to be specifically relevant to the Irish context—these were feeling "embarrassed about dementia in the family" and "not wanting neighbours to know".

The 42 enabler statements were identified primarily at the individual and community levels. In particular, it was reported that "hearing personal stories of living with dementia" helped to "humanise people with dementia", and this was perceived as being a crucial enabler, raising awareness of the lived experience of dementia among the public. Thus, this criterion was fulfilled (Table 4).

Feasibility and acceptability of the intervention content, delivery, and fidelity assessments (Objective 5)

Intervention content.

One benchmark of feasibility and acceptability of the intervention content was captured through attendance (with a criterion of minimum 60% attendance in each intervention component). People with dementia attended an average of 96% of the CST sessions (range: 86–100%), and 79% of the eight exercise sessions (range: 50–100%). Reasons for non-attendance included *carer being unable to bring the person with dementia to sessions* ($n=2$), *recovery of the person with dementia from a medical procedure* ($n=1$), and *person with dementia or caregiver having prior commitments* ($n=2$). Attendance at the educational component was high: Caregivers attended 91% of their educational programme (range: 67–100%); 33 people attended the dementia awareness event, and seven local GPs attended the GP education workshop (the maximum capacity was eight). Thus, the criteria for attendance were fulfilled (Table 4).

Feedback relating to the intervention content was gathered via evaluations and participant monitoring progress

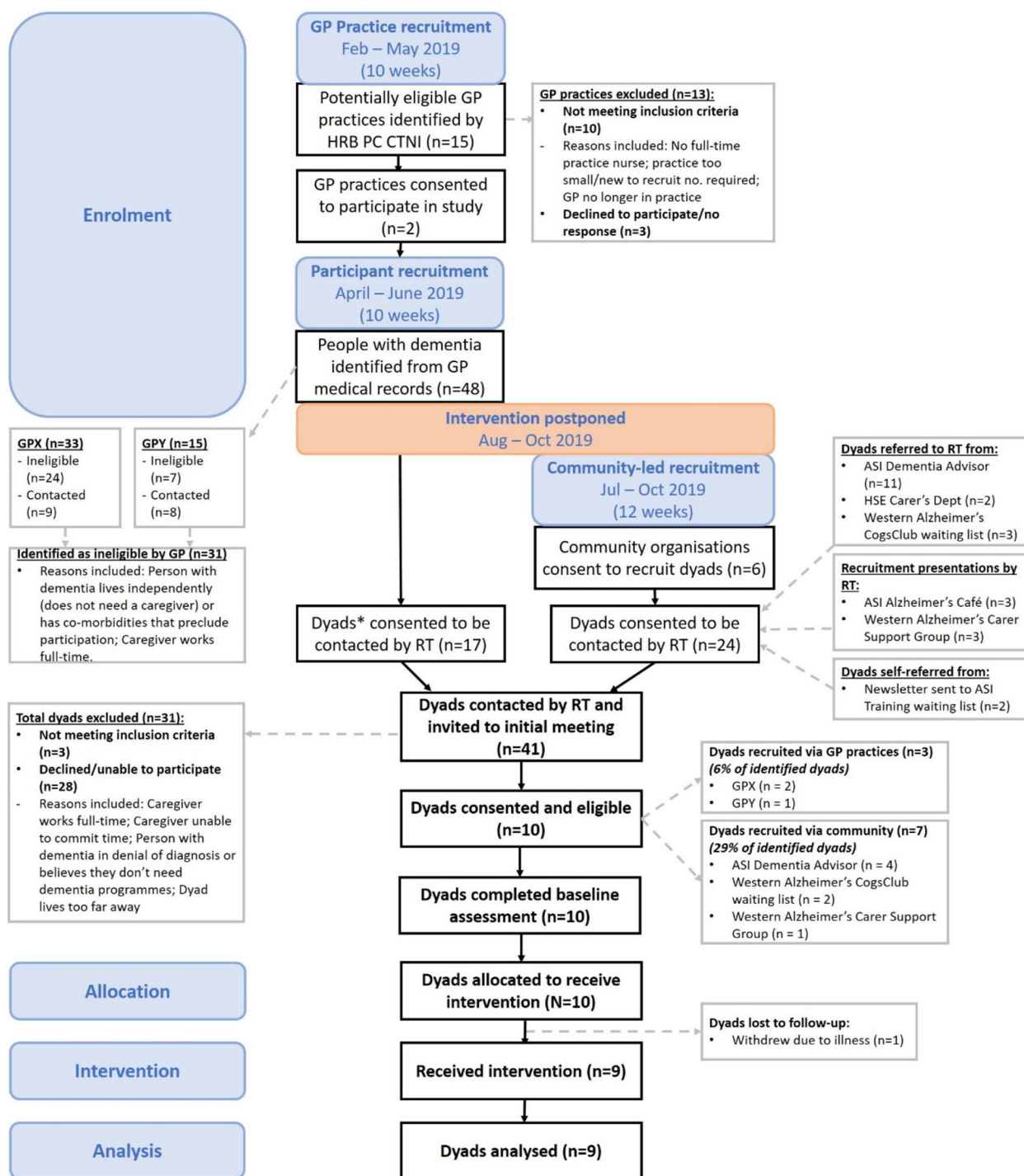


Fig. 2 Flow of participants through the CREST study

forms (CST only). Overall, the evaluations were positive, indicating that the content and delivery were acceptable.

The CST participant monitoring progress forms indicated that the majority of the people with dementia

engaged well with the activities in each session (average score: 82–86%) and that interest and enjoyment were particularly high for certain sessions (e.g. *Session 3: Childhood*, *Session 14: Team Quiz*). People with dementia

commented that they particularly enjoyed the social aspect of the sessions and found it easy to engage with the content:

“Got to know each other better through today’s topic” (group feedback, Session 5)

“Fun atmosphere but still informative” (group feedback, Session 14)

While some people with dementia reported that they felt their cognition had improved:

“My memory is a bit sharper” (Person with dementia 6, process interview)

“I was very bad at the beginning but by the end I felt I got something out of it” (Person with dementia 5, post-intervention interview)

These statements were echoed by some of the caregivers, and a GP.

“Now every day you’ll see her reading newspapers, whereas before she only glanced through it ... now you can hear her reading every page. And now that she’s reading more she’s talking more ... The more she talks, the more words she finds” (Caregiver 1, post-intervention interview)

“[Person with dementia 3] was more chatty and talkative. And she had more confidence you know? She started a thing in the lockdown, of walking up and down and dressing up in a hat ... And she had a bit of a sense of humour - she knew that we were smiling seeing her pass and waiting to see what she would be wearing today!” (GP 2, post-intervention interview)

The evaluation of the content of the exercise component also attracted positive comments from the majority of the people with dementia, who indicated that they found the exercises manageable and appreciated that modifications were available to suit all mobility levels (for instance, completing some exercises while seated). These comments were taken as an indication that the content was feasible and acceptable. As with the CST component, people with dementia enjoyed the social aspects of the programme such as chatting with each other and the older adults:

“Whereas we were in our own group, and it was great. And I looked forward to meeting them every day it was on ... You’d be chatting to them and saying, “How did the week go?” and you know they were in the same situation as I was” (Person with dementia 8, process interview).

The older adults reported that the training programme they received prior to the exercise component was feasible and acceptable, stating that it helped them to

communicate better with people with dementia, and they felt more confident to assist the person with dementia.

The content of the three education programmes (caregiver, community and GP education programmes) was also positively evaluated by the respective participants. The caregivers’ evaluations of the programme were very positive with an average participant rating of 99% across the six sessions (range: 94–100%), indicating that the caregivers found the content feasible and acceptable. The group-based nature of the education sessions was crucial to the caregivers’ enjoyment of the component: they appreciated meeting others who would understand their situation, where they could share their experiences and advice with each other.

“...there’s a group of us who are in the same situation. It was nice to have that inclusiveness to kind of go with and say look, we’re all here for a common goal” (Caregiver 1, post-intervention interview).

Most caregivers reported that the content was easy to follow, and all found the information helpful and relevant. Some caregivers were already implementing the communication strategies learned in CREST, and one remarked that they were getting along better with the person they cared for as a result.

“[Now] I find that if I have a smiley face and a softer voice, it defuses the situation much better ... I hadn’t thought about that kind of communication” (Caregiver 6, post-intervention interview)

Most of the attendee evaluations from the community focused dementia education programme ($n=33$) indicated that the content was relevant and that it had increased their understanding of dementia and for some it changed their perceptions of people with dementia: “It showed a different way of looking at [dementia]” (Attendee 22). However, the guest speaker with dementia’s account of living with Lewy Body, although deemed impactful was identified by most caregivers as potentially upsetting for people with dementia and suggested that future sessions might discuss a less extreme type of dementia, or describe how they are living as well as possible with their dementia.

The GPs ($n=7$) who attended the GP dementia training workshop (the GP PREPARED programme) also positively evaluated the content, finding it relevant to their daily practice. They reported that their knowledge of dementia had improved, including the benefits of making a timely diagnosis, and they reported that they felt more confident in delivering post-diagnostic care to patients. Some GPs indicated that they had been unaware of local dementia supports and services and would advise their patients about these going forward.

Table 5 Primary response QoL-AD at baseline, post-intervention and improvement

QoL_AD Total	Baseline (n = 9)	Post Intervention (n = 9)	Improvement in QoL-AD (n = 9)
Mean (SD)	37.1 (3.70)	39.3 (4.41)	1.84 (6.74)
Median [Min, Max]	37.5 [32.0, 43.0]	38.0 [34.6, 46.0]	0 [- 8.00, 14.0]

Overall, the content of the three components of CREST were considered to be feasible and acceptable to the participants, fulfilling this criterion (Table 4).

Intervention delivery

The feasibility and acceptability of the delivery of the intervention content was confirmed by the positive feedback given by all study participants. These comments related to the facilitators, venues and scheduling of each component. In terms of duration, some people with dementia expressed a desire for more time for discussion in the CST component, but all other groups reported that the planned duration of sessions was feasible and acceptable.

The facilitators for each component praised the programme content and the flexibility of their respective programme manuals; The CST facilitators appreciated that the activities could be modified to accommodate individual capabilities in the group and reported no issues with delivery. The exercise facilitator found the programme content acceptable and feasible but reported some challenges with monitoring the exercise circuit class due to the large group size (9 pairs) and the varying mobility levels of the people with dementia. In addition, some of the people with dementia forgot how to do the exercises correctly, requiring continuous monitoring and exercise demonstrations by the facilitator in a short 3-min window (the exercise programme included 10×3-min circuits (Fig. 1)). The exercise facilitator suggested that it would have been helpful if the co-facilitator had a background in exercise and so could have helped with demonstrating the technique for the different exercises. All of the programme content outlined in the carer's programme manual was delivered within the programme duration by the facilitator and was feasible and acceptable to them. Overall, the delivery style of the three CREST components were considered feasible and acceptable (Table 4); with some minor recommendations for use in a future trial (Table 7).

Fidelity assessments

Overall, programme fidelity for each component was high and facilitators encouraged participation, clearly

communicated with people with dementia, and delivered the content at an appropriate pace.

In the earlier sessions of the CST component, the content was felt to be a bit 'rushed' ($n=3$) or participants were late ($n=2$), and once the facilitator gave unclear instructions before an activity, but these issues were all quickly resolved. However, both CST co-facilitators reported that the fidelity assessment form was time consuming and unhelpful with the description/layout of the session each week always being the same and there being overlap between some of the indicators, e.g. "encourages participation" versus "empowered the group". They recommended that the format of the fidelity form should be a Yes/No checklist similar to the adherence form.

Overall, the criteria for progression for this objective regarding programme fidelity were considered to have been met (Table 4).

Follow-up rates, outcome completion and adherence or compliance rates, and reasons for non-adherence (Objectives 6 and 7)

Follow-up rates Nine dyads completed the CREST intervention (90% retention rate; 10% lost to follow up), fulfilling this criterion for progression (" < 20% of participants would be lost to follow-up") (Table 4).

Outcome completion All outcome measures were completed by the respective participants at baseline and post-intervention with a completion rate of 100% (see Table 2.). Total missing data items within each measure was low (<5%) at both baseline and post-intervention; the listed reasons for missing items included *participants overlooking the item rather than skipping it due to difficulty* ($n=3$), and *researcher error* (e.g. *incorrect response option included on the Zarit Burden Interview (ZBI) measure (item 22) at baseline*) ($n=10$): Consequently, Item 22 was removed from analysis for all participants (10 items); this amount of missing data was within the acceptable limits of the ZBI [36].

Summary statistics for the primary response QoL-AD at baseline, post-intervention and as a change score are given in Table 5.

Table 6 Completion of secondary outcome measures by the CREST groups

Outcome	Recommended time (min)	Completion Time in minutes (SD)		Missing data (total <i>n</i> of missing items, %)	
		Baseline	Post-intervention	Baseline	Post-intervention
People with dementia					
QoL-AD	10–15	10.8 (7.27)	7.57 (4.76)	0 (0)	1 (0.86)
EQ-5D-5L	3–5	4.90 (1.29)	5.33 (2.24)	0 (0)	0 (0)
GDS	5–7	6.10 (2.64)	7.13 (2.85)	1 (0.67)	0 (0)
MMSE	10–15	10.2 (3.42)	15.5 (8.49)	0 (0)	0 (0)
PPOM	5–10	8.80 (3.79)	9.57 (5.50)	0 (0)	0 (0)
SIS	10	14.7 (7.39)	12.5 (4.07)	0 (0)	0 (0)
Caregiver					
AC-QoL	10	8.4 (2.17)	9.25 (4.17)	0 (0)	0 (0)
DK-20	15	13.3 (2.54)	12.3 (5.57)	5 (2.55)	0 (0)
RUD-lite	15	12.5 (3.72)	- (-)	2 (0.8)	0 (0)
SSCQ	5	4.04 (2.41)	3.75 (1.28)	0 (0)	0 (0)
ZBI	10	9.0 (4.08)	8.25 (4.13)	11 (5)	1 (0.5)
Older adults					
DAS	5–10	12.3 (5.12)	10.7 (7.18)	0 (0)	0 (0)
DK-20	15	15.1 (4.34)	22.7 (16.1)	0 (0)	1 (0.006)

AC-QoL Adult Carer Quality of Life, DAS Dementia Attitudes Scale, DK-20 Dementia Knowledge-20, EQ-5D-5L European Quality of Life (EuroQoL) 5 Dimension scale, GDS Geriatric Depression Scale, MMSE Mini-Mental State Exam, PPOM Positive Psychology Outcome Measure, QoL-AD Quality of Life – Alzheimer’s Disease (care recipient version), RUD-lite Resource Utilisation in Dementia – lite version, SIS Stigma Impact Scale, SSCQ Short Sense of Competency Questionnaire, ZBI Zarit Burden Interview

The outcome measures were generally completed within the timeframe recommended by the instrument authors, except for the Stigma Impact Scale (SIS) [31] completed by people with dementia, the Dementia Knowledge-20 (DK-20) [34] and Dementia Attitudes Scale (DAS) [35] completed by older adults (Table 6). The reasons reported for difficulty in completing the SIS [31] included having too many options; finding it difficult to follow the response options (as these are numbers rather than words); and feeling the statements did not apply to them. In addition, some statements on the SIS [31] prompted reflection and therefore required additional time to think about the answers. The older adults completed the DK-20 [34] and DAS [35] at home, in their own time and self-recorded completion times. Some stated that the measures were difficult, feeling that they did not have enough knowledge about

dementia to answer correctly, with one person stating they had to really think about the answer and another that they did some research in order to find the correct answer. This may have added to the completion times recorded (Table 5).

Caregivers completed the RUD-lite [39] post-intervention. However, the accurate completion times for this instrument could not be calculated as it was completed simultaneously with the Travel and Private Expenses form. In total, the average completion time for both instruments was 18.5 min suggesting that without the expenses form, the RUD-lite [39] which has a recommended completion time of 15 min could have been completed within the recommended time.

Overall, the secondary outcome measures (Table 5) were rated as either “very easy” or “easy” to complete at baseline (range 60–80%) and post-intervention (range

Table 7 Key recommendations for changes to the CREST intervention

Component	Recommendation	Suggested by	Timeline for implementing the change
CST	Longer time for discussion in sessions	People with dementia, Facilitator	In a future trial
	Larger print on handouts	Facilitator	Immediately
	Personalising the “faces/scenes” activity with local or family member photos in Session 6 as participants might not recognise famous faces	Facilitator	In a future trial
Exercise	The co-facilitator should have an exercise background so they can monitor and demonstrate the correct exercise techniques alongside the exercise facilitator	Older adults	In a future trial
	The exercise pairs should be matched and have a chance to get to know each other in advance of the exercise programme	Older adults	In a future trial
	The training for older adults should include a practical demonstration of each exercise	Older adults	In a future trial
	Tea/coffee should be served at the end rather than the start of sessions, to allow everyone more time to chat	Older adults	In a future trial
Caregiver dementia education	Longer sessions to allow time for discussion:* - Sessions were originally 90–110 min each - Feedback after the first session (100 min) indicated this was not long enough - The remaining 5 sessions were modified, so all sessions lasted 120 min each (12 h total)	Caregivers, Facilitators	Immediately
	A video (Session 1) was not appropriate and should be removed (it featured a caregiver discussing caring for a relative with advanced dementia, which some caregivers found distressing)	Caregivers	Immediately
	A guest speaker should come in to discuss supports and services for caregivers	Caregivers	Immediately (added to Session 6)
	The scoring on the session evaluation form should be simplified from a 5-point scale to a 3-point scale	Caregivers	Immediately
Community awareness event	Similar events should be organised more frequently, both locally and nationwide	Community event attendees	In a future trial
	A video case study would be useful, if a guest speaker was unavailable for future events	Community event attendees	In a future trial
	The guest speaker’s speech should be reviewed beforehand, to fully ensure the focus of the content is suitable for the audience	Community event attendees	In a future trial
GP education workshop	Facilitators should provide additional information on locally available dementia supports and services	GP workshop attendees	In a future trial

*This differed from the original protocol [21]

50–90%). There were a few ratings of “difficult” by people with dementia in completing the: EQ-5D-5L [33] ($n=1$ at baseline), MMSE [29] ($n=1$ at baseline and $n=2$ post-intervention), the Positive Psychology Outcome Measure (PPOM) [32] ($n=1$ at baseline) and the Stigma Impact Scale (SIS) [31] ($n=2$ post intervention). In addition, there were a few ratings of “difficult” among the caregivers: Adult Carer Quality of Life (AC-QoL) [38] ($n=2$ post intervention), DK-20 [34] ($n=1$ at baseline), RUD-lite [39] ($n=2$ at baseline) and Short Sense of Competency Questionnaire (SSCQ) [37] ($n=1$ post intervention).

The older adults reported difficulties with completing both the DAS [35] ($n=3$ at baseline and $n=2$ post intervention) and the DK-20 [34] ($n=5$ at baseline and $n=7$

post intervention). For the DK-20 [34], the older adults stated that the difficulty at baseline was associated with feeling they lacked the knowledge to answer specific questions (e.g. those relating to dementia knowledge or appropriate behaviours towards people with dementia). At post-intervention, a larger number of older adults reported that they still found completion “difficult” (78%; $n=7$). For all other measures (QoL-AD [28], EQ-5D-5L [33], Geriatric Depression Scale (GDS) [30], MMSE [29], PPOM [32], SIS [31], AC-QoL [38], SSCQ [37] and ZBI [36]), the high levels of outcome completion across participant groupings indicated that the measures were feasible and acceptable, fulfilling the established criteria for progress.

Missing data were handled as per the manual guidelines for that respective measure. For example, guidance on the QoL-AD [28] notes that if a participant omits more than two missing items, the entire measure should be considered missing (if fewer than two missing items, the QoL-AD score for that participant should be calculated as an average of the remaining items). Where specific guidelines were not stated for missing data, a total score was calculated by summing the remaining items. Although the percentage of missing data was low, it could still introduce bias if certain items were consistently overlooked. The incorrect response options were printed on the ZBI tool for item 22 due to researcher error and this resulted in treating this item as missing data for all caregivers at baseline, indicating the need for accurate data collection methods to prevent such errors.

Adherence

Average adherence rates across all CST sessions were high, calculated as 98% by the facilitators and co-facilitators (range group 1: 98–99%; group 2: 97–98%). Reasons for non-adherence were as follows: *first session ran out of time (e.g. did not start on time due to late arrival of one person with dementia) (n=1); people with dementia having difficulties (e.g. could not read small newspaper print) (n=2)* (Table 4).

Adherence to the exercise component was also high, with average session adherence calculated at 98% by the facilitator, co-facilitator, and older adults (range: 97–99%). Reasons for non-adherence were as follows: *technical difficulties in session one (e.g. no laptop to display presentation) (n=1); people with dementia having difficulties (e.g. difficulties remembering how to do the exercises correctly each week) (n=3)*. However, adherence to completing the home exercise diaries was low, with only 37% of the expected weekly diaries completed. No participant completed all seven diaries, and one-third of the group ($n=3$) did not complete any diary entries. The main reason for non-adherence was due to the fact that the *people with dementia forgot to complete them* (Table 4).

The criterion for Fitbit adherence to assess activity levels or sleep quality was set at $\geq 70\%$ wear by people with dementia across the 8-week exercise programme (this was calculated manually from the synced data uploaded from each device). The challenges of using a Fitbit among this cohort have been described in further detail [44]. In short, for people with dementia adherence to wearing the Fitbit met this criterion during the day (80%) but fell below the cut-off at night (67%), with an average of 13 missing days (range: 0–55 days) and 21 missing nights per participant (range: 0–59 nights) (Table 4). Reasons

for non-adherence were as follows: *people with dementia forgot to wear the Fitbit (n=2); discomfort (wrist-strap was itchy or tight) (n=1); wrist-strap broke (n=1)*. Thus, the self-completed home-exercise diary and use of Fitbit were not adhered to at a sufficient level and were therefore not considered feasible for use with people with dementia.

Finally, adherence to the three educational components was high. For the caregiver programme, average adherence across all sessions was 98%. Reasons for non-adherence were due to the fact that the first session ran over time (the timing for each week was subsequently reviewed and increased) and a technical difficulty with one video when the volume was too low to hear. Adherence to the delivery of the community dementia awareness event, and GP education workshop, was 100%. Therefore, the criteria for progression were partially met for objective 6 in that average adherence to intervention content was high: CST: 98%; Exercise: 98%; Education (caregivers; community; GPs): 98–100% adherence. However, adherence to secondary exercise measures was low: home exercise diary (37%); Fitbit wear acceptable during daytime (80%) but not night-time (67%). Adherence for objective 7 was fully met in that reasons were identified by participants for non-adherence and non-attendance (Table 4).

Acceptability of the recruitment process, assessments, data collection tools, intervention (Objective 8) (content and delivery to participants already presented in Objective 5)

Recruitment process People with dementia and caregivers completed recruitment feasibility questionnaires, which indicated that the recruitment process was feasible and acceptable to them, fulfilling this criterion (Table 4). They reported that the information packs were helpful and informative: all found the study information sheet easy to understand, and most found the consent forms easy to complete (people with dementia: 86% ($n=8$); caregiver: 100% ($n=9$)). This was also supported in the post-intervention interviews where people with dementia and caregivers reported that the information was easy to understand:

“Straightforward, understandable terminology”
(Person with dementia 2)

“The information was laid out clearly” (Caregiver 7)

All participants found the reminder letter and phone call helpful, and no aspect of the recruitment process was rated “unhelpful” by either people with dementia or caregivers.

Assessments and data collection tools

Initially, adherence to intervention content was to be confirmed by people with dementia completing an adherence form. However, in the CST sessions, most people with dementia were unable to complete the form without assistance. As a result, feedback from the people with dementia was gathered verbally as a group at the end of the CST sessions and recorded on a flipchart. This method was found to be more feasible and acceptable. Feedback on adherence to the exercise component was then also collected verbally which differed to the original protocol [21] whereby it was stated that it would be collected by researchers from people with dementia using a written adherence form.

In the caregiver education component, in the first session, two caregivers reported difficulties with the form (“hard to complete late at night”, “felt rushed at the end of the session”), no issues were reported in the subsequent sessions with caregivers reporting that the adherence form was easy to complete. The facilitators and co-facilitators of the CST adherence forms found them to be feasible and acceptable to complete and praised the structure of the form (which listed the specific content and activities for each session with a “Yes/No” checklist), as it allowed them to recap the session easily and add comments if desired. The methods used in CREST to measure adherence were suitable to use in a future trial, fulfilling this criterion (Table 4).

Session evaluations

Caregiver feedback at the end of their first education session indicated that the 5-point rating scale (1 = “Strongly Agree” to 5 = “Strongly Disagree”) on the evaluation form was too complicated. Therefore, the form was redesigned with a 3-point scale (Agree/Neutral/Disagree). After this change, all caregivers reported that the evaluation form was feasible and acceptable to complete. Attendees at the dementia awareness event and GP education workshop were not asked to rate the ease of completion of their evaluation forms, though there was no missing data, indicating that the forms were most likely acceptable to complete. Therefore, all the evaluation forms were considered suitable to use, fulfilling this criterion (Table 4).

Baseline score and variability of secondary outcome measures among participants to inform sample size estimates for a future definitive trial (Objective 9)

Sample size estimates for a future definitive trial were calculated from the improvement (i.e. Post – Baseline) in QoL-AD measure completed by the people with dementia [28]. The sample size was based on a two-sided, two-sample *t*-test with 80% power at the 0.05 significance level to detect a difference in mean improvement

of 3 units between the intervention and control groups, assuming a standard deviation of the improvement score of 7 (Table 5). This difference corresponds to a standardised mean difference of 0.43, in line with previous research [47]. If it is assumed that an attrition rate of 20% is likely, a total sample size of 210 (105 people per arm) would need to be recruited for a future RCT, with randomisation and allocation performed at the dementia/caregiver dyad level.

Evaluation of cost analyses process (Objective 10)

The cost analysis of implementing the CREST intervention was estimated at approximately €2922 per patient. In terms of the total healthcare cost, the mean cost per patient over the 15 weeks was €4932 (SD: 4569.19). In terms of health outcomes, mean QALYs gained per patient at 15 weeks was 0.23 (SD: 0.03). The analysis confirms that it would be feasible to conduct a full health economic evaluation under appropriate guidelines from the Health Information and Quality Authority (HIQA) [48], were a full randomised controlled trial to be conducted, fulfilling this criterion (Additional file 5).

Recommendations

Participants made some key recommended changes to the different intervention components and measurement tools (Table 7). Some recommendations were implemented immediately, and others will be implemented in any future trial.

Discussion

This study aimed to investigate the acceptability and feasibility of the CREST intervention. The intervention consisted of three different components, the content and delivery of which were found to be acceptable, with a very high completion rate and overall positive feedback. The study also aimed to test the feasibility and acceptability of the chosen secondary outcome measures for use in a future definitive trial. Generally, these were feasible and acceptable and completed in line with the parameters for each respective instrument. The high adherence rates observed in the study (96% for CST sessions, 79% for exercise sessions and 91% for caregiver education sessions) indicate strong engagement and the perceived value of the intervention components by the participants. In addition, the high adherence rates also validate the intervention’s design and implementation, demonstrating that it is feasible to deliver these components. However, significant difficulties with recruitment impacted the delivery of the intervention as the number of GP practices who agreed to participate fell below target. Community-based recruitment was identified as an acceptable alternative, but this recruitment strategy would benefit

from a further feasibility study whereby there is a multi-faceted recruitment strategy that includes both GP practices and community-based approaches.

Where possible, throughout the CREST intervention, recommendations from participants regarding changes to the intervention or data collection methods were enacted during the study so their feasibility and acceptability could be assessed. “Personhood” is a driving principle of the National Dementia Strategy in Ireland, and the needs of people with dementia should always be at the heart of dementia research [49]. This includes both amplifying the preferences and reducing potential burden [50]. In this regard, the CREST feasibility study placed people with dementia and their families at the heart of the intervention, engaging them throughout in research that was relevant and sensitive to their needs [1]. However, though the majority of the feasibility and acceptability criteria were broadly achieved to indicate that the CREST intervention could be run as intended, the current recruitment strategy was not feasible, and this reduced the viability of the overall intervention.

The CST component attracted an exceptional level of attendance (96%), far exceeding the average 73% attendance noted in a previous review of CST programmes [51]. The exercise component was equally popular, with attendance on par with a similar exercise-based intervention for people with mild to moderate Alzheimer’s disease [52]. The social aspects of both components were appreciated and frequently mentioned by participants. This reflects the findings from previous studies, where social interaction provided a motivating factor to participate [52], and group-based exercise formats attracted higher adherence and enjoyment for people with dementia [53] and healthy older adults [54], when compared against individual/solo exercise programmes. Adherence to the exercise programme was also high. Generally, adherence by people with dementia to exercise-based interventions is greatest when the exercises focus on aerobic activity and strength (such as those in CREST) as participants feel these provide the most tangible benefits to their health [53, 55, 56].

However, the feasibility of the secondary exercise measures was not confirmed due to poor completion and adherence to the home exercise diaries (35%) and night-time Fitbit wear (67%). As regards the home exercise diary, future use could be improved by asking the caregiver to continually remind the people with dementia to complete the diary [55, 56]. While adherence to wearing the Fitbit during the day was acceptable (79%), challenges remain in identifying how to effectively use such technology with people with dementia [46].

The educational components of the intervention were generally considered feasible and acceptable by

all participants. As with the people with dementia, the caregivers lauded the social interaction that occurred, commented on the value of being able to meet people in a similar situation and to share experiences with and learn from each other. These sentiments echo previous remarks that a caregiver’s social needs were as vital as their physical health needs, to combat social isolation and loneliness [57, 58]. In addition, caregivers found the educational information was helpful and they felt more capable of communicating with people with dementia (and, in particular, in dealing with responsive behaviours); these comments reflect previous findings from similar psychosocial interventions for caregivers which included education on behaviour management [59, 60]. The participants at the CREST community education event reported increased understanding of dementia and a change in their perception of people with dementia. These findings were similar to a larger-scale study in Ireland which evaluated the HSE’s “Understand Together” information campaign (upon which the CREST community event was based) [61]. However, it must be acknowledged that the CREST event was a once-off, and the impact or retention of this knowledge may be short lived.

The GPs who participated in the CREST educational workshop indicated that they felt more confident in diagnosing dementia and providing post-diagnostic care. This is important because GPs are often the first point of contact when a person experiences cognitive changes and early diagnosis is a vital aspect of dementia care provision [62]. However, GPs in Ireland and elsewhere can lack confidence in diagnosing dementia [63, 64] and can feel under-equipped to provide families with adequate information on care and services during and after diagnosis [17, 18, 65, 66].

Despite most of the feasibility objectives being achieved in this study, the recruitment strategy was not feasible, and this reduced the viability of the overall intervention. Difficulties with recruitment have been identified in previous dementia research [67–71]. In the CREST study, initially, low uptake by local GP practices hindered access to participants and delayed the commencement of the intervention. Requests for information on why eligible GP practices declined was not provided so it is unclear what barriers to GP recruitment were; more widely, self-reported barriers to the recruitment of GPs in primary research include existing workload, a lack of time [72, 73] and involvement in research being a low priority when there are competing demands [69, 74].

Recruitment of people with dementia was further hampered by the need for their caregiver to also participate which, as indicated in the literature, can impact the willingness of people with dementia to participate in research [75] and it can be perceived as time consuming

especially if caregivers are working or have additional obligations [76]. In addition, while none of the participants explicitly indicated concerns with the number of questionnaires to be completed, it is possible that the number of measures used may have negatively impacted recruitment. Some people with dementia declined to participate due to a reluctance to accept their dementia diagnosis and feeling that they were not “bad enough” to need the intervention; these reasons were also reported in a recent UK trial which experienced similar delays due to low uptake by eligible dyads [77]. The perceived stigma or “embarrassment” of a dementia diagnosis was also a reason for not participating in the intervention. Stigma was identified in the social marketing data, where “embarrassment” and “not wanting neighbours to know” were identified as barriers to participation. This is in line with previous findings that stigma presents significant barriers to participating in dementia research for both people with dementia and their caregivers [78, 79] and highlights the ongoing importance of campaigns such as *Dementia: Understand Together*, to increase public awareness and understanding of dementia in Ireland [80] and *What Makes You, You from Alzheimer Europe* [81].

The alternative recruitment strategy employed in this study through local dementia advocacy and community support organisations proved much more successful, with the majority of participants recruited via this strategy. Previous research also reported success using a similar approach, involving collaboration with a range of services to identify eligible participants [75, 82]. Community organisations in the CREST study attracted twice the number of dyads as GPs in much less time (3 months versus 5 months); thus, it is possible that the community approach may have eventually recruited the desired sample size if recruitment was extended for longer and to a much wider geographical area. However, a second feasibility trial would be needed to test these recruitment methods further.

Furthermore, sample size calculations from the feasibility study indicate that a minimum of 210 dyads would be required to evaluate CREST in a full-scale RCT and achieving this number may significantly lengthen the duration of the recruitment phase of the study. Elsewhere, opportunities for people with dementia to participate in research in communities across the US [83] and the UK [84] have been shared on online research registries; a similar registry is currently in development in Ireland, with the eventual intention to support dementia research activities, including recruitment [85]. Since the CREST study was completed “*TeamUp for Dementia Research*” [86] has been established which is a service where people living with dementia and current or former

family carers can register their interest in participating in dementia research. Initiatives such as this will help to overcome some of the challenges that were faced in the CREST study and can support future feasibility/definitive trial research. Such registries have been successful in supporting recruitment to studies [69, 76, 87] but they do require resource support, to remain updated and effective [76]. There is a need in Ireland to explore ways of incentivising research in community settings similar to that in the UK whereby Primary Care can be “incentivised” to become a patient identification centre with service support costs being provided externally in addition to the research funding [88]. This could also enhance recruitment. Another initiative in Ireland includes *Dementia Trials Ireland*, which aims to enable every person at risk of, or living with dementia in Ireland, the opportunity to access clinical trials [89].

The chosen secondary outcome data collection tools for the CREST feasibility study were feasible and acceptable and completed in line with the parameters for each respective instrument. Only one measure, the DK-20, was rated “difficult” by older adults at both baseline and at follow-up, and average completion times far exceeded recommendations (22 min versus 15 min). Some older adults reported that they struggled to answer specific questions about challenging behaviours due to a lack of knowledge or contact with people with dementia; unlike the caregivers who would be well-versed in managing behaviours considered to be challenging or aggressive, allowing them to complete the measure quickly and confidently. It should also be noted that the measure was designed for untrained frontline care staff, and specific dementia knowledge is not a prerequisite [34]. However, as the older adults still reported the measure to be difficult even after spending time with people with dementia during the exercise component, it may be that a more comprehensive training session on dementia prior to the exercise component should be included going forward. Data on completion times for secondary outcome measures is rarely reported in studies; however, CREST provided the completion times for this population for all of the secondary outcome measures used. Completion time and evaluation of each measure were important markers in CREST, to ensure the “full and equal participation” of people with dementia, rather than relying on proxies such as caregivers [50]. This was guided by the principle that all aspects of an intervention for people with dementia should be sensitive to their needs and expectations [1]. Overall, while feedback was given to improve the usability of some specific tools (e.g. shorter rating scales), the majority of data collection tools were considered suitable in their existing form.

Strengths and limitations

The study was comprehensive in assessing the feasibility and acceptability of both the intervention and the research measurement tools used. Written and verbal feedback was collected from those receiving and delivering the intervention, ensuring that a wide range of views were ascertained. As with any feasibility study, the ability to generalise the findings is constrained by the small sample size and specific location in which it was conducted. The lack of a control group and no blinding means that there may have been selection bias in that only those motivated to participate took part in CREST. While the fidelity and adherence to the CREST intervention were monitored through detailed forms completed by the facilitators, co-facilitators and participants, the findings might have been influenced by observer bias whereby facilitators might have unconsciously rated adherence and engagement more favourably and social desirability bias, where the people with dementia and their caregivers may have reported more positive adherence to present themselves in a favourable light.

In this study, the majority of the people with dementia/caregiver dyads lived near a city and were affiliated with local dementia organisations; thus, their perspectives may not represent all people with dementia (particularly those with less access to support resources). Finally, the delivery of the intervention was completed just prior to the start of the COVID-19 pandemic and so post intervention interviews with GPs and staff who had assisted in recruitment were delayed and were significantly shorter than other groups; if participants had had more time for these interviews they may have provided stronger insight and further enriched our findings.

Conclusion

This feasibility study demonstrates that while overall the components of the CREST intervention were feasible and acceptable to all the participants, significant difficulties with recruitment impacted the delivery of the intervention in the community.

Further feasibility work is therefore needed to enhance and modify the recruitment strategies before a larger-scale RCT can be conducted. This work should include examining the simultaneous engagement of both primary care and community organisations in recruitment, refining the intervention components to better meet diverse participant needs and undertaking additional qualitative research to further explore the barriers and facilitators to recruiting people with dementia to a trial.

Abbreviations

AC-QoL	Adult Carer Quality of Life
CREST	Comprehensive Resilience-building psychosocial Intervention
CST	Cognitive Stimulation Therapy

DAS	Dementia Attitudes Scale
DK-20	Dementia Knowledge-20
EQ-5D-5L	European Quality of Life (EuroQoL) 5 Dimension scale
GDS	Geriatric Depression Scale
GP	General Practitioner
HRB	Health Research Board
HIQA	Health Information and Quality Authority
MMSE	Mini-Mental State Exam
PPOM	Positive Psychology Outcome Measure
PREPARED	Primary Care Education, Pathways and Research of Dementia
PRINCE	Pulmonary Rehabilitation Programme for people with Chronic Obstructive Pulmonary Disease in Primary Care
QALY	Quality-Adjusted Life Years
QoL-AD	Quality of Life in Alzheimer's Disease
RCT	Randomised controlled trial
RUD-lite	Resource Utilisation in Dementia – lite version
SIS	Stigma Impact Scale
SSCQ	Short Sense of Competency Questionnaire
ZBI	Zarit Burden Interview

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40814-024-01568-3>.

Supplementary Material 1.
Supplementary Material 2.
Supplementary Material 3.
Supplementary Material 4.

Acknowledgements

The authors wish to acknowledge the CREST Dementia Advisory Forum and the study participants and facilitators.

Authors' contributions

DC, KM, DD and B Woods conceived and designed the study. GW, DC, KM, CC and RMD conceived the theoretical framework. DC, KM, B Woods, KIL, GW, TF, SS, PD, NG and FT contributed to developing the intervention components. JN and JA performed the statistical analyses and CD the social marketing component. DC, SS, PD and NG conducted the data collection and were involved in data analysis and interpretation alongside JA and GOS. KM and CD were involved in social marketing analysis and PG and AH conducted the economic analysis. AWM, PD, NG, DC and DD contributed to developing and implementing the recruitment process. DC and GOS wrote the first draft of the manuscript, DC and B Whelan revised and finalised the draft. All authors read and approved the final manuscript.

Funding

The funding for this study was obtained from the Health Research Board (HRB) following a peer review process. The HRB had no role in the design of the study, the collection, analysis and interpretation of data, or in writing the manuscript.

Data availability

Data is available from the corresponding author upon reasonable request. The protocol for this intervention can be accessed here: <https://doi.org/https://doi.org/10.1186/s40814-020-00701-2>

Declarations

Ethics approval and consent to participate

Ethical approval for the study was granted by University of Galway Research Ethics Committee (Ref: 16-Feb-03). Consent to participate was obtained from all participants.

Consent for publication

Consent for publication is not applicable.

Competing interests

The authors declare that they have no competing interests.

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Received: 25 October 2023 Accepted: 29 October 2024

Published online: 09 November 2024

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