

Co-adapting the GRACE (Goal-diRected ACcessible, Equitable, Evidence-based Care) Dementia Post-diagnostic Support Intervention to Improve Inclusivity

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Abstract

Background

Evidence-based post-diagnostic dementia support is not equitably available in routine care. GRACE (Goal-diRected ACcessible, Equitable, evidence-based Care) is a manualised, goal-focused programme for people living with dementia and family carers (GRACE-family), developed with a complementary workforce intervention for home care staff (GRACE-professional). GRACE has demonstrated clinical and cost-effectiveness in trial settings, providing a strong foundation for wider implementation. We aimed to co-adapt GRACE to optimise its inclusivity and fit with diverse populations and service contexts, and to systematically report both the resulting adaptations and the co-adaptation process itself.

Methods

Between 2025 and 2026, a co-adaptation group comprising people with lived, professional and academic experience integrated work from eleven co-adaptation workshops with 19 people with lived experience of dementia and 38 with professional and/or academic experience. Observational field notes, workshop notes, participant interview transcripts and successive intervention manual drafts were analysed. We used deductive thematic analysis to characterise the co-adaptation process and documented modifications using the Framework for Reporting Adaptations and Modifications to Evidence-based Interventions (FRAME) to document modifications.

Results

Two themes characterised the adaptation process: *designing for all intended beneficiaries*, by strengthening the voice of people living with dementia and improving cultural, linguistic and disability accessibility; and *balancing flexibility with fidelity*, by adapting content, session structure and delivery while preserving the intervention's core functions. Adaptations included a new module on care-home transitions and a tailored introductory session for people diagnosed in hospital; improved accessibility for people with learning disabilities and people with low literacy; modifications to enable peer delivery of GRACE-professional by home-care workers; and linguistic and cultural changes for delivery in Urdu and Hindi. The co-adaptation process involved sustained collaborative problem-solving but also highlighted tensions around the assumptions underpinning the dyadic intervention model and the limits of adapting an existing intervention.

Conclusions

This study highlights co-adaptation as an equity-oriented implementation strategy and demonstrates the value of combining structured adaptation reporting with participatory methods. GRACE is now ready for

implementation and evaluation in routine dementia care to assess whether these modifications improve the equitable reach, uptake and experience of post-diagnostic support.

Plain English Summary

After a dementia diagnosis, good support is not equally available to everyone. GRACE is a structured programme that helps people living with dementia and their family carers set and work towards personal goals, alongside a related programme that trains home care staff to provide similar support. Earlier research showed GRACE works well and is good value for money. This study used a co-adaptation approach, working with people with different experiences and expertise to make GRACE more inclusive, while keeping the key parts that make it effective.

To do this, we brought together people living with dementia, family carers, care staff, and researchers in eleven workshops over 2025-2026, alongside interviews and review of earlier programme materials, to identify and agree changes together. Two key themes emerged.

First, the team worked to give people living with dementia a stronger voice and make the programme better for people from different cultural and linguistic backgrounds and people with disabilities. Second, the team balanced making changes with keeping the parts of GRACE that make it effective. Changes included a new session for people considering a move into a care home, extra support for people diagnosed in hospital, Urdu and Hindi versions, and a way for trained care workers to deliver parts of the programme to peers.

This collaborative approach offers a model for making evidence-based dementia support fairer and more accessible. GRACE is now ready to be tested in everyday care to see if these changes help more people get the support they need.

Introduction

Dementia is a growing global health challenge. Currently, one million people in the UK live with dementia, where it is the leading cause of death (1), and annual care costs are projected to reach £90 billion by 2040 (2). Most people living with dementia wish to remain at home, and nearly two-thirds do; however, unmet needs, declining self-management, home safety risks and carer burden often lead to breakdown of independent living, resulting in unplanned hospital admissions or moves to care homes (3).

The *10 Year Health Plan for England* (4) outlines a shift towards community-based care that prevents crises and reduces unplanned hospital use. If this is achieved, one outcome might be enablement of people with dementia to remain at home for longer. Proactive post-diagnostic dementia care could improve quality of community care, however, current provision remains inequitable (5). People from certain minority ethnic groups receive less preventive care (6), for reasons including a reluctance to engage with health and social dementia care services that they do not perceive as culturally competent (7, 8). People from more deprived backgrounds are more likely to be diagnosed in hospital following an

admission rather than in the community. Such diagnoses happen later and make it harder to plan and access post-diagnostic care, which increases the risk of poor outcomes for those affected (9).

Goal-focused interventions offer a personalised and structured approach to care planning and delivery, providing a means of addressing some of the inequities inherent in one-size-fits-all models. Recent trial evidence demonstrates that people with mild dementia can set goals and improve everyday functioning in relation to them (10). For those with greater cognitive or functional impairment, support will be needed to identify and work towards goals that reflect their values and preferences, most often provided by family or friends (henceforth “family carers”) (11).

GRACE-family (Goal-diRected ACcessible, Equitable, evidence-based Care; originally NIDUS-family [New Interventions for Independence in Dementia]) is a manualised, modular psychosocial support intervention tailored to goals set by dyads of people with dementia and family carers, where possible – with the person with dementia supported to participate as far as they are able. Facilitators support dyads to set goals around the support needs of the person with dementia, then provide 4 to 8 tailored sessions selected from a structured menu (see Fig. 1 for overview of GRACE intervention), followed by 2 to 4 brief follow-up calls over one year. To extend these principles across health and social care, GRACE-professional (originally NIDUS-professional) was developed as a six-session group programme for home care staff, delivered by two non-clinical facilitators. Complementary to GRACE-family, it creates a shared approach to post-diagnostic dementia support, strengthens care integration, and extends the benefits of goal-focused, person-centred care to people with dementia who do not have a family carer by embedding these principles within home care practice (12, 13).

Both interventions were co-designed with people affected by dementia, including people living with dementia and family carers (14). A randomised controlled trial has shown GRACE-family to be both effective and cost-effective (15) in supporting people with dementia and family carers to achieve their care goals, and pre-implementation work found health and social care services willing to adopt it (16). In the original trial, goals were set by family carers alone in 258/302 dyads (85%) and jointly by the dyad in only 44/302 (15%), which led some of our group to question whether it is possible to further strengthen the involvement of people with dementia in goal-setting.

Interventions that succeed in trials often fail to realise their anticipated benefits in real-world settings, a phenomenon sometimes referred to as “voltage drop”(17, 18). Collaboration with end-users can help bridge this implementation gap, ensuring interventions reflect diverse cultural and contextual needs and fostering the ownership required for sustainable delivery (19). Adaptations are “*intentional modification(s) of an evidence-informed intervention to achieve a better fit between an intervention and a new context*” (20) and co-adaptation refers to the process of agreeing and specifying adaptations through shared decision-making with stakeholders in order to enhance an intervention’s relevance, appropriateness and effectiveness for specific populations (21).

We are now scaling GRACE for routine delivery within integrated health and care systems in the UK, beginning in areas with diverse, underserved populations and high deprivation. This paper describes how

we co-adapted GRACE (GRACE-family and GRACE-professional) to better meet the needs of people living with dementia and family carers, including adaptations to support access across diagnostic pathways, reduce cultural, learning and language barriers, and address challenges such as transitions into care homes. Our objectives were to: (1) systematically report the adaptations made and the rationale for each; and (2) explore how the co-adaptation process reflected our framework for meaningfully engaging diverse types of experience.

Methods

We obtained approval from the National Research Ethics Service and HRA approval on 7 October 2025 (approval number 25/LO/0657).

Study design and approach

Due to our focus on health inequalities, we supplemented the GRACE theoretical model underpinning the original GRACE intervention development (22, 23), with Baumann and Cabassa's framework for co-producing implementation strategies to reduce inequalities (24). We previously identified the core components and "adaptable periphery" of GRACE - the elements considered amenable to adaptation without compromising the components responsible for clinical and cost-effectiveness (25). Our stakeholder engagement approach was guided by five dimensions relevant to the process of co-adaptation: multi-stakeholder collaborative action; co-learning towards innovation; contextual knowledge production; generating meaning (prioritising how co-creation is meaningful for the participating stakeholders over time); and open, trustful and inclusive dialogue (26).

Co-adaptation group

The co-adaptation group, co-chaired by ND and MR, met quarterly from August 2025 to August 2026 and provided the central forum for multi-stakeholder shared decision-making throughout the adaptation process. Members were drawn from those involved in the initial development of the interventions as well as others who joined the group applying for the GRACE funding due to their complementary expertise. While we sought to balance lived, professional and academic expertise, as well as representation across ethnicity, gender and geography, the group was small; members therefore sought to be cognoscente of gaps in lived or professional expertise and to account for this when recruiting to workshops or interpreting findings.

Approximately five professional and academic members attended each meeting, with membership varying according to the expertise required for specific discussions. These included psychiatrists (RB, JR, AA, SB), a nurse academic (CCa), and academic researchers (HDK, CCo, ND, JB). The group also included representatives from two dementia advocacy organisations and two patient and public involvement (PPI) co-researchers with lived experience as family carers (MR and RP) who chaired the

GRACE PPI group (comprising eight people with lived direct or carer experience of dementia), enabling two-way dialogue between groups.

During development of the funding application for the GRACE programme in 2024–25, the group (who at that time comprised all those initialised above) identified five priority areas for adaptation. This was revisited in the initial co-adaptation workshop, and ideas refined into a series of planned co-adaptation workshops to develop five new elements enhancing:

1. reducing distress around transitions into care homes;
2. relevance of GRACE-family for people with learning disabilities and dementia;
3. reach of GRACE-professional through peer-delivery training by home care workers;
4. reach of GRACE-family to people diagnosed with dementia following unplanned hospital admissions; and
5. accessibility for people unable to access GRACE-family in English and/or with low literacy.

Figure 2 illustrates how co-adaptation activities were integrated with the underpinning frameworks (24). At least three members of the co-adaptation group, representing lived, clinical and academic experience, attended every co-adaptation workshop to ensure continuity across the five new elements. We sought to ensure that decision-making processes, and resolution of differing views were resolved in accordance with the values of our stakeholder engagement framework; we describe below times when conflicts arose and were not readily resolved through discussion. Where necessary, the co-chief investigators of GRACE (CC, JB) met with the PPI group leads (MR and RP) and also consulted with the co-adaptation group chair (ND) to resolve these challenges, using the framework to guide decision-making.

Co-adaptation workshops

We recruited people with lived experience (people living with dementia and family carers) and professional expertise relevant to each of the five adaptation areas. Lived experience participants were recruited through partner community organisations across the four initial GRACE implementation regions (Yorkshire, Kent, North East London and Belfast), national organisations, social media and public meetings. Potential participants contacted the research team directly or completed an online form describing their background and experience, which we used to purposively recruit participants with relevant experience, including those who self-identified as coming from the underserved groups that were the focus of the planned adaptations. Professional and clinical participants were recruited through existing networks, including regional organisations involved in planned GRACE implementation.

Five co-adaptation workshop series were conducted, one for each new element. Each comprised an initial ~ 2.5-hour in-person workshop, followed approximately one month later by a 45-to-90-minute online workshop to review draft materials developed by the research team, with oversight of the co-adaptation group. Workshops were held primarily at the university, with a workshop dedicated to learning disabilities hosted by a learning disability charity and the hospital diagnosis workshop at a district

general hospital, both within regions where GRACE implementation is planned. For the hospital diagnosis adaptation, an additional workshop was held with people living with dementia to explore how GRACE-family could be introduced following a hospital diagnosis. Participants unable to attend follow-up workshops were invited to comment on draft materials by email or in a separate meeting, and drafts of materials were circulated to participants for comment by email, telephone or in person, according to preference. Participants received vouchers (£25 to £50 depending on meeting length) in recognition of their contribution. Throughout, workshops were underpinned by principles of equitable partnership that valued and integrated different forms of expertise.

Data collection

Before each workshop, participants completed an online survey (Qualtrics) capturing sociodemographic characteristics (age group, gender, ethnicity and, for lived experience participants, first language) and relevant experience. Researchers supported participants to complete this via phone call if required.

Co-adaptation workshop dialogue was recorded in three ways:

1. Observation: Researchers experienced in observational methods (CC, AD) attended each workshop as non-participant observers and recorded field notes (27).
2. Workshop documentation: Detailed notes and accessible summaries were circulated after each meeting, enabling participants to confirm, challenge or refine decisions, reducing power imbalances.
3. Participant interviews: Participants attending workshops were invited to complete brief video-recorded interviews about their experience of the co-adaptation process, lasting 5–10 minutes and following a topic guide co-designed with the core group, comprising two questions: “What motivated you to take part today, and why is it important to you?” and “What are you taking away from today's session?”.

Analysis

Participant characteristics were summarised. Our source data for analyses of co-adaptation activities were: workshop observational field notes, meeting notes, interview transcripts, and successive versions of co-adapted materials.

To address our first objective, proposed modifications were prospectively documented using the Framework for Reporting Adaptations and Modifications to Evidence-based Interventions (FRAME). Following each co-adaptation workshop, modifications were reviewed and coded against FRAME domains, including what was modified, the nature and rationale for the change, who proposed it, contextual drivers, and whether changes related to intervention content or implementation. The resulting FRAME matrix provided an audit trail documenting how GRACE materials evolved through stakeholder input (28).

To address our second objective, we conducted code book thematic analysis (29) using the five co-creation dimensions of our underpinning theoretical framework (26). Data were systematically coded into meaningful fragments and labelled with initial codes; two researchers (from CC, HDK, CMcA and AOA) coded each workshop’s data independently, meeting iteratively to develop a shared coding frame, before organising the data into preliminary themes aligned with our research objectives.

Each workshop was initially analysed as an individual “case study” (Appendix). Data displays summarising early findings were then reviewed by the GRACE PPI group (comprising 4 family carers and 2 people living with dementia, including four who had attended workshops as participants). Their feedback informed development of themes.

Results

Tables 1a and 1b list the characteristics of participants with lived and professional experience, respectively. Table 2 summarises the data generated in co-adaptation workshops conducted between October 2025 and July 2026.

Table 1
a: Sociodemographic characteristics for workshop attendees with lived experience

Participant ID	Gender	Ethnicity	Age	Highest level of education	Type of experience	First language
L1	Female	Bangladeshi	45+	PhD	Former carer	Urdu
L2	Male	Pakistani	45+	Degree	Former carer	English
L3	Female	White UK	45+	Secondary	Current carer	English
L4	Female	Bangladeshi	30–45	Secondary	Current carer	Bengali
L5	Female	White UK	45+	Degree/postgraduate	Former carer	English
L6	Female	British Sikh	45+	Secondary	Former carer	Punjabi
L7	Female	White UK	45+	No secondary education	Learning disability	English
L8	Male	White UK	< 30	Unable to specify	Learning disability	English
L9	Female	White UK	45+	Diploma	Current carer with professional learning disability experience	English
L10	Female	British - Bangladeshi	30–45	Degree/Postgraduate	Former carer	Bengali
L11	Male	British – Indian	45+	Post secondary	Current carer	Gujrati
L12	Female	White UK	45+	Degree/Postgraduate	Former carer	English
L13	Male	White UK	45+	Further Education	Former carer	English
L14	Male	White UK	45 +	NR	Diagnosed dementia, 20 years	English
L15	Female	White UK	45+	NR	Diagnosed dementia, NR	English
L16	Female	White UK	45 +	NR	Diagnosed dementia, 10 years	English

Abbreviations: NR, not reported

Participant ID	Gender	Ethnicity	Age	Highest level of education	Type of experience	First language
L17	Female	White UK	45+	NR	Diagnosed dementia, 9 years	English
L18	Male	White UK	45+	NR	Diagnosed dementia, 11 years	English
L19	Male	White UK	45+	NR	Diagnosed dementia, 8 years	English
Abbreviations: NR, not reported						

Table 1

b: Sociodemographic characteristics for workshop attendees with professional experience

Participant ID	Gender	Ethnicity	Age range	Role	Duration in role
P1	Female	White UK	45+	Charity associate	2 years
P2	Female	White UK	30–45	Research consultant	2 years
P3	Male	White UK	45+	Charity manager	2.3 years
P4	Female	White UK	30–45	Deputy charity manager	4 years
P5	Male	Black/British - African	30–45+	Senior support worker	2 years
P6	Female	White UK	45+	Support worker	5 years
P7	Female	Black/Black British – African	30–45	Dementia coordinator	1.5 years
P8	Female	Any other White background	30–45	Doctor	4.5 years
P9	Female	White UK	30–45	Learning disability nurse	8 years
P10	Male	Mixed White & Asian	30–45	Consultant doctor	1.5 years
P11	Female	Any other Mixed/Multiple ethnic background	30–45	Occupational therapist	3 years
P12	Male	Asian/Asian British – Indian	30–45	Consultant psychiatrist	3 months
P13	Female	Any other White Background	30–45	Consultant psychiatrist	12 years
P14	Female	White UK	Under 30	Occupational therapist	11 months
P15	Female	White UK	30–45	Doctor	10 years 8 months
P16	Female	Any other White Background	45+	Consultant	12 years
P17	Female	White UK	45+	Dementia outreach coordinator	10 years
P18	Female	White UK	45+	Speech and language specialist	20 years
P19	Female	White UK	45+	Dementia advisor	9 years
Abbreviations: NR, not reported					

Participant ID	Gender	Ethnicity	Age range	Role	Duration in role
P20	Female	White UK	30–45	Consultant geriatrician	1 year
P21	Female	White UK	45+	Clinical nurse specialist	4 years
P22	Female	Asian/Asian British - Indian	30–45	General practitioner	8 years
P23	Female	Asian/Asian British - Pakistani	NR	Interpreter	26 years
P24	Female	Asian/Asian British - Pakistani	45+	Interpreter	7 years
P25	Female	Not reported	Under 30	Research assistant	6 months
P26	Female	Asian/Asian British - Bangladeshi	Under 30	Research assistant	6 months
P27	Female	Asian/Asian British – Indian	Under 30	Research assistant	1 year 11 months
P28	Female	White UK	30–45	Homecare manager	17 years
P29	Male	Black/Black British Caribbean	45+	Homecare director	9 years 5 months
P30	Male	Asian/Asian British - Indian	Under 30	Community engagement officer	1 year
P31	Female	White UK	45+	Homecare director	9 years 5 months
P32	Male	Asian/Asian British Bangladeshi	45+	Homecare manager	7 years
P33	Male	Asian/Asian British – Pakistani	30–45	Homecare manager	3 years 1 month
P34	Male	Asian/Asian British - Indian	30–45	Regional operation manager	15 years
P35	Male	White UK	30–45	Community engagement & dementia awareness coordinator	10 years
P36	Female	White UK	30–45	Training and Development Coordinator	1 year 9 months
P37	Female	White UK	Under 30	Study support facilitator	NR
Abbreviations: NR, not reported					

Participant ID	Gender	Ethnicity	Age range	Role	Duration in role
P38	Female	White UK	Under 30	Service facilitator	NR
P39	Male	Any other Asian background	45+	Clinical research practitioner	6 years
Abbreviations: NR, not reported					

Table 2
Description of workshops - attendees and data collected

Topic	Date	Modalities and duration	Coadaptation participants	University researchers	Data produced
Workshop series 1: Care transitions	20.10.25	In-person (2.5 hours)	L1, L2, L3, L4, L5, L6, P1, P2	CCo, CCa, HDK, JB, CD	Field notes Minutes Interviews
	24.11.25	Online (45 minutes)	L1, L2, L3, L4, L5, L6, P1, P2	CCo, CCa, HDK, JB, CD	
Workshop series 2: Learning disability	20.2.26	In-person (2 hours)	P3, P4, P5, P6, P7, P8, P9	JB, JR, SB, AA, AD	Field notes Minutes Interviews
	10.04.26	In person 1:1 interview (20 minutes)	L7, L8	AD, SB	Field notes
	24.04.26	Online (50 minutes)	L9, P3, P4, P5, P6, P7, P9	SB, HDK, JB, AA, AD, JR	Minutes
Workshop series 3: GRACE professional	18.3.26	In-person (2.5 hours)	L2, P28, P29, P30, P31, P32, P33, P34, P35, P36, P37, P38, P39	CCo, HDK, AD, ES	Field notes Minutes Interviews
	15.4.26	Online (50 minutes)	L2, P28, P30, P32, P33, P35, P36, P37	CCo, HDK, ES	Minutes
Workshop series 4: Diagnosis in hospital	1.5.26	In-person (2 hours)	L5, L10, L11, L12, L13, P10, P11, P12, P13, P14, P15, P16, P17, P18, P19, P20, P21	CCo, HDK, JB, ES	Field notes Minutes Interviews
	22.6.26	Online (50 minutes)	L10, L11, P11, P18, P19, P20	CCo, JB, HDK, AD, AOA	Minutes
	25.6.26	Online lived experience meeting (90 minutes)	L14, L15, L16, L17, L18, L19	Patient advocate facilitator, HDK, JBu, CCo, AD	Field notes Minutes

Topic	Date	Modalities and duration	Coadaptation participants	University researchers	Data produced
Workshop series 5: Language and literacy	5.5.26	In-person (2 hours)	L2, L10, P22, P23, P24, P25, P26, P27	CCo, AD, HDK, JB	Field notes Minutes Interviews
	2.7.26	Online (40 minutes)	L2, L11, P24, P27	HDK, JB, AD, AOA	Minutes

Objective 1: Adaptations made and the rationales for making them

Across the workshops, participants co-produced adaptations with intentions to extend the reach, accessibility and implementation of GRACE while preserving its core functions. The co-adaptation agreed by the group were: a new module supporting transitions from home to residential care; revised text and images across seven modules to improve accessibility for people with learning disabilities; separate versions of five modules for people with dementia and for carers; an introductory session tailored to people diagnosed in hospital, with the person-with-dementia version split into two shorter sessions; and Urdu and Hindi versions of all materials, linguistically and culturally adapted. GRACE-professional was adapted for peer delivery by home care workers (as opposed to by external facilitators as in the original feasibility trial (12)), with paper and digital copies of manuals. The co-adaptation group also developed professional videos in which they, and others with lived experience of dementia and trained facilitators role-played all GRACE-family sessions and the first two GRACE-professional sessions to support facilitator training.

While FRAME captured *what* was adapted, our qualitative analysis explored *how* these adaptations were developed. Two themes characterised the co-adaptation process: designing for all intended beneficiaries; and balancing flexibility with fidelity. These are summarised below and in Table 3, while each of the five workshops (listed in the methods) are presented as “*case studies*” in the Appendix, providing greater detail of how each contributed material to these overarching themes.

Table 3

Cross-case themes and corresponding FRAME adaptation types identified across the five co-production workshops

Cross-case theme	Predominant FRAME adaptation types	Examples	Workshop series
Designing interventions to fit all intended beneficiaries	Tailoring/tweaking/refining; Loosening structure Adding elements	Flexibility to encompass deliver primarily to person with dementia or carer, diagnosis in hospital, to fit with needs of people with learning, or physical disabilities and with young onset dementia, multilingual resources, inclusive language, multimedia	All 5
Balancing fidelity with flexibility	Spreading sessions Substituting components	<p>Delivery to paid support worker considered where appropriate, for people with learning disability in non-residential supported living</p> <p>Peer delivery in home care agencies; simplified homework, split sessions, alternative wellbeing activities, digital manuals</p> <p>Splitting the session for people diagnosed with dementia in hospital</p> <p>Recordings in place of manuals for low literacy/ some dialects</p>	2,3,4,5

Designing for all intended beneficiaries

Most FRAME modifications involved **tailoring or refining** existing intervention content with the intention of improving accessibility, reach or relevance while preserving GRACE's core functions. Where co-adaptation workshops recommended **adding elements**, these were to ensure the intervention were as inclusive as possible of people with dementia and accommodated diverse cultural, linguistic and communication needs.

Strengthening the voice of people with dementia

In workshop series 1 (reducing distress around transitions into care homes), 2 (relevance of GRACE-family for people with learning disabilities and dementia) and 4 (reach of GRACE-family to people diagnosed with dementia following unplanned hospital admissions) there was a focus on adaptations to ensure the intervention empowered and supported both the person with dementia and the carer. Co-producers of the new care home transition module described carers' tension in "*balancing obligations, guilt and duty with need*" [field notes, workshop 1], respecting a person's right to remain at home while

acknowledging risk and carer strain. The group developed a structured decision tool that comprised part of the new module material, to elicit different perspectives around a care home move.

The importance that the intervention empowered the person with dementia was also evident in workshop 2 discussions, where people with learning disabilities described experiences of being spoken about rather than to:

“Make sure asking me questions, not just going to my mum.” [L8, person with a learning disability, workshop 2]

A challenge raised by a person with dementia in workshop series 4 informed the group’s decision to add module versions where the language was directed at the person diagnosed with dementia, and to structure the initial session to allow for the person diagnosed with dementia to have an first meeting with the facilitator alone if they would like to:

“With the best will in the world if the carer is there, they will talk for them. Important person living with dementia is spoken with alone first. Who owns the goals? My husband could send completely different goals that I would want.” [L17, person diagnosed with dementia, workshop 4]

The same group proposed **tailoring** of language: that materials refer to the *“diagnosed person”* rather than the person *“lived with”* [L15, person diagnosed with dementia, workshop 4], and argued that *“people with dementia need to be asked first”* [L17, person diagnosed with dementia, workshop 4]. The co-adaptation group balanced these views against the fact that joint goal-setting with family carers is a core component of the effective intervention and produced a two-part introductory session: people diagnosed with dementia could, where appropriate, be supported to explore possible goals alone, with the dyad brought together only in the second part.

Supporting underserved communities

Three workshop series (1, 2 and 5 [accessibility for people unable to access GRACE-family in English and/or with low literacy]) describe modifications to manuals to increase reach to underserved communities; the remaining two (3 [reach of GRACE-professional through peer-delivery training by home care workers] and 4) developed care pathways enabling post-diagnostic support to be received in hospital or domiciliary social care settings, aiming to enhance inclusivity by reaching people less able to access secondary community care.

In workshop 1, co-producers described the challenge of stigma within some communities

“... around kind of cultural context” [P2, professional, workshop 1]. The group added quotes directly to the manual to acknowledge this, including:

“Will I be judged by my community? Everyone's journey is different.” [L2, family carer, workshop 1]

By naming the stigma workshop participants reported experiencing from minoritised communities around care homes, they hoped to support those receiving the intervention to reframe their situation.

In workshop 2, co-producers refined language, for example, noting that people with learning disabilities *“already at baseline have difficulties”* [P3, professional, workshop 2] and updated images to be more inclusive by reflecting people with younger-onset dementia or living with physical disabilities.

Workshop 5 aimed to extend reach to other linguistic communities by focusing on dialect and everyday, conversational rather than formal language. The group initially planned to use a professional interpreting service to produce an everyday Urdu version, while core team members with the relevant language skills, assisted by AI translated the introductory session into Hindi. At the second workshop, the group considered the Hindi version acceptable. However, they found that while the Urdu version had been translated accurately at a linguistic level, it lacked sufficient cultural adaptation, equivalent to *“Shakespearean English”* [L2, family carer, workshop 5]. As a result, the language sounded too formal and was judged to be less accessible for many intended beneficiaries, with the group asking for more: *“simple everyday language”* [P24, professional, workshop 5].

The group also developed plans to maximise inclusivity when the intervention is delivered via an interpreter, by making an audio recording of the booklet, an approach they judged would work well for people with low literacy from any linguistic background. A participant who worked as an interpreter first proposed this:

“So anyone who can’t actually physically read it, they can just listen to the recording, which we feel like will increase accessibility”. [P26, professional, workshop 5]

The group discussed offering this as a standard option to everyone, rather than requiring individuals to request it. This could help reduce the embarrassment or stigma that people with low literacy may experience when asking for support, *“by increasing accessibility”*. It would also avoid singling people out based on their literacy levels, as this is an option that many people may choose to use regardless of their literacy skills. An adaptation was also proposed to facilitator training to encompass working with interpreters to convey the context and nuances of the intervention, rather than straight forward interpreting which may not give context or nuances, in other words moving toward a more holistic interpretation, as opposed to direct linguistic translations of terms.

Balancing fidelity with flexibility

A common theme across workshops was how to maintain GRACE's core components while improving fit with planned delivery populations and contexts. Proposed adaptations included **substituting components** and **redistributing content across sessions**. Written exercises and homework activities were simplified to reduce participant burden, and sessions for people diagnosed during hospital admission were divided for the same reason. Participants also recommended **substituting intervention components** by, for example, offering alternatives to mindfulness exercises or supplementing written

materials with video demonstrations, to preserve the intended therapeutic function while increasing accessibility.

Workshop 3 addressed co-adaptation of GRACE-professional for delivery by home care workers. The group noted that some components of the existing intervention risked creating discomfort in a peer-led setting. For example, at one attendee's suggestion, the group replaced personal questions such as *"What skills do you bring?"* with broader, less personal prompts such as:

"What skills are important for a home care worker to have?" [P28, professional, workshop 3]

There was a group consensus of support for offering materials in multiple formats, including professionally produced paper workbooks, PDFs, mobile-friendly resources and e-learning platforms, proposed by agency managers mindful of the shift from analogue to digital, *"paperless"* care. When considering how to *"train the trainer"*, there was consensus that short role-play videos of intervention delivery could be particularly effective for demonstrating communication techniques and relationship-centred care:

"Preferred learning styles, videos can be quite powerful." [P36, professional, workshop 3]

In workshop 2, one participants said:

"There is also a potential challenge for GRACE around the family carer focus. Many people with a learning disability do not have a spouse or children. If this relies on parents they are likely to be less around as people get older" [L9, family carer with professional experience, workshop 2]

The group then discussed how GRACE-family delivery to a dyad comprising a person with a learning disability and dementia and their paid support worker could work well in some circumstances, given that in group homes there is often *"a family dynamic"* [field notes, workshop 2]. This challenged the group to consider the intervention as a flexible tool, unconstrained in real-world practice by the inclusion criteria of a clinical trial. This discussion moved the flexibility-fidelity balance uncomfortably far from fidelity for the academic members, who commented that this may *"stretch the evidence too far"*. Ultimately, however, this did not influence the types of adaptation made, but perhaps heralded the degree to which materials may be adopted in a broader range of circumstances in practice than in the original trial.

Objective 2: How co-adaptation reflected our framework for engaging different types of experience

Across all workshops, adaptations emerged through dialogue between researchers, practitioners, people with dementia, family carers and community representatives, who drew on different sources of expertise to improve reach and acceptability for groups and contexts that are often poorly served by existing dementia care pathways.

Ten of the eleven workshops included all the intended elements of our co-creation process. In one workshop, however, field notes indicated that trustful dialogue was not always achieved between researchers, professionals and people with dementia. Some lived-experience members questioned the scope for meaningful co-adaptation once an intervention, albeit a co-produced one, has already been developed and evaluated:

"It's already complete, already happening, should have asked us two years ago" [L14, person diagnosed with dementia, workshop 4]

They also felt that the concept of a dyadic intervention was inherently flawed:

"Cannot make something that is a useful tool for people with dementia and their family carers, need two separate tools." [L14, person diagnosed with dementia, workshop 4]

This view appeared to arise from beliefs that everyone with dementia could make their own decisions without support of a carer, if sufficiently empowered:

"People in hospital that are suspected of having dementia, staff might think they need their care givers to advocate for them, however if they were actually given a bit more time or were well and not in hospital, chances are a lot of them would be able to make that decision themselves" [L17, person diagnosed with dementia, workshop 4]

These views dominated discussion, but other participants in the group expressed different view, including one member who commented that:

"I understand and agree with a lot of what is in the booklet." [L17, person diagnosed with dementia, workshop 4]

The co-adaptation group discussed how to reconcile the very different views regarding whether a dyadic intervention could be, for some, the preferred format where the person with dementia *"may no longer be comfortable in a situation with two separate tools where the person they rely on might be excluded"*, or whether this was inherently disabling of the person with dementia.

This workshop nonetheless reflected other elements of the co-creation process. Strongly held beliefs drove **co-learning towards innovation**: lived-experience co-producers were initially skeptical that anyone was diagnosed with dementia in hospital, and researchers shared evidence that around a fifth of diagnoses are made this way (12). This exchange generated contextual knowledge, and the co-production group used the resulting feedback to strengthen inclusive language for people with dementia throughout the materials.

Discussion

Building on an intervention with established clinical and cost-effectiveness, the co-adaptation process produced a set of targeted modifications intended to improve reach and acceptability for groups and contexts that are often poorly served by existing dementia care pathways. These included a new module to support transitions to care homes, adapted materials for people with learning disabilities and dementia, a hospital-tailored introductory pathway for people diagnosed during admission, linguistically and culturally adapted materials in Urdu and Hindi, alongside strategies to support people with low literacy, and peer-delivery adaptations for GRACE-professional in home-care agencies. Across these changes, two cross-cutting findings emerged: the importance and challenges of designing for all intended beneficiaries, and the need to balance flexibility with fidelity to the core components of the intervention.

Reflecting experiences of previous groups modifying interventions to improve reach (30), and implementation guidance that interventions should be deliberately modified to fit new contexts while preserving their active ingredients (24), most adaptations were refinements rather than full redesigns: changing wording, revising images, reformatting sessions, adding new examples, and tailoring delivery processes to new contexts.

A central focus of the co-adaptation process, that arose from workshops rather than being predetermined by the co-adaptation group, was to make the intervention more explicitly inclusive of the person diagnosed with dementia, not only the family carer. Although GRACE-family remains a dyadic intervention and family carers continue to play a key role in goal-setting and implementation, workshop discussions repeatedly highlighted the risk that the person with dementia could be spoken for rather than spoken with. The resulting adaptations, including providing new versions of five of the modules for delivery to the person with dementia as the primary recipient, more direct prompts to the person with dementia, and splitting the introductory session into two shorter parts, the first of which could be delivered to the person with dementia alone, reflect an effort to preserve the dyadic structure while strengthening autonomy, voice and participation.

For the learning disability and language adaptation workshops, accessibility meant shifting the frame from fixed ability to changes in functioning, appropriate for people with lifelong learning disabilities, and using images reflecting disability and younger-onset dementia. The language workshops highlighted that translation can fail if it does not account for dialect, everyday speech, and dementia literacy. The proposal to provide audio-recorded materials or encourage participants to record sessions on their own phones demonstrates how accessibility can be normalised rather than framed as a special accommodation for a minority of users. These findings align with wider critiques of dementia services that remain organised around monolingual, literate and culturally dominant assumptions, despite clear evidence of unequal access and poorer experiences among minoritised ethnic communities and other underserved groups (8, 25).

The co-adaptations also aim to address structural inequities in access by expanding GRACE into hospital diagnosis pathways and home care agencies, responding to the fact that many people are diagnosed in

hospital (12), are underserved by specialist memory services, and that home care workers often support clients with dementia with little or no training (32). People diagnosed in hospital often have multiple comorbidities, fewer support networks, and experience greater deprivation (12); the co-adaptation process proposed adaptations to meet these needs, such as gentler pacing, and explicit acknowledgement of shock and uncertainty. Adapting GRACE-professional for peer delivery in home care agencies embeds support in settings where people with dementia already receive care, rather than relying solely on specialist health services.

One of the strengths of this study was the explicit use of a stakeholder engagement framework. Across most workshops, this enabled dialogue between stakeholders who brought different kinds of knowledge: lived knowledge of stigma, guilt and relationship strain, practitioner knowledge of workflow, discharge systems and workforce constraints, and academic knowledge of intervention theory, trial evidence and implementation science.

Co-adaptation nonetheless has limits and tensions. The research team's existing relationship with the intervention, alongside their roles in facilitating workshops, developing adaptations and analysing data, created tensions in one workshop, where those not involved from the outset questioned what they could bring to the process. People living with dementia who helped develop the original intervention eight years earlier could no longer take part due to the progressive nature of dementia. Involving new people therefore provided opportunities to bring different direct dementia experience and challenge to the original intervention. Concerns have, however, been expressed that people who actively participate in PPIE may not represent the wider dementia population, with previous research noting that those who participate often have relatively mild cognitive difficulties (31). By triangulating the experience of people with dementia who were able to participate, with voices of family carers of those with more advanced dementia, we sought to hear a broad range of perspectives from potential users of the intervention. Co-adaptation does not erase pre-existing power relations, and "participation" can feel constrained when core features are already fixed by prior evidence, particularly in implementation-focused work where the task is to modify the adaptable periphery while retaining core components. Reporting these tensions is important if the field is to avoid idealised accounts of co-production that underplay conflict and practical constraint.

Other limitations include that workshops and analysis were conducted in English, which may have constrained participation and depth of contribution in the language adaptation work. Further, although stakeholders were purposively recruited for diversity, some groups may remain under-represented relative to the broader populations GRACE intends to benefit.

This study offers a model for making dementia support more responsive to people often marginal to mainstream post-diagnostic pathways, those diagnosed in hospital, with learning disabilities, or facing language or literacy barriers. The next stage will evaluate implementation outcomes for the adapted GRACE programme in real world settings.

Declarations

Ethics approval and consent to participate

This study obtained approval from the National Research Ethics Service and HRA approval on 7 October 2025 (approval number 25/LO/0657).

Consent for publication

All public contributors gave informed consent for anonymised quotations to be published.

Competing interests

None declared.

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Author Contribution

CCo, JB and HD-K conceived the paper. HD-K and CCo wrote the manuscript. All authors were involved in critiquing and revising the manuscript. All authors read and approved the final manuscript.

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Data Availability

All GRACE intervention materials are freely available online.

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Appendix

Appendix - Case studies of workshop series

Bold denotes elements of the implementation and co-creation process frameworks reflected in the data

Workshop series 1: Developing the care transitions module

This element was **designed with vulnerable populations in mind**, specifically minority ethnic cultural groups in whom high levels of stigma around care homes use are reported(8). This was acknowledged in workshop discussions, for example in this next quote from a family carer:

"I believe that with the south Asian perspective there's the stigma around moving patient from home to care facility" [L2, family carer]

Members shared relevant resources, supporting **co-learning towards innovation**: the DECIDE decision tool for family carers and people with dementia considering a move to a care home, developed by academic members (33); and a lived experience member discussed a resource for family carers about shared care with care home staff. Co-creators **produced contextual knowledge**, as an academic researcher reflected in relation to a trend towards minority ethnic groups accessing care homes more:

"I think there's some particular challenges today that I think were really interesting around kind of cultural context. That potentially we might be seeing an increase in South Asian families in particular accessing care homes or having to make use of them and how do we best support them" [P2, professional]

Several interviewees described the workshops as enabling **open trustful and inclusive dialogues**, as in this next quote from a family carer:

"We went through the process with my mother-in-law of getting her into a care home and parts of that were very rewarding experience and parts of that proved to be quite difficult and I felt we had a story to tell and things that other people could learn from" [L5, family carer].

Field notes from the in-person workshop record how this developed into **multi stakeholder collaborative action**:

[Members] frequently drew on their personal experiences and emotions to suggest small but meaningful revisions. Even minor wording changes were treated as significant, as they could affect the tone and impact of statements or quotations.

This group worked collaboratively to **generate meaning**, by tailoring the intervention materials to co-creators needs. Co-designed material acknowledged the emotions and stigma that a care home move can evoke, for example by including quotes from lived experience members:

"Will I be judged by my community? Should I be doing more?" and "Everyone's journey is different" [L2, family carer]

Discussions acknowledged tensions in delivering an inclusive intervention that empowered the person living with dementia and the carer. Meeting minutes record discussions around the challenge for carers in *"balancing obligations, guilt & duty with need"*; respecting a person's right to remain at home, while balancing this with risks and carer strain. They responded to this by co-designing a structured discussion to develop plans that could empower dyads to make informed choices, for example by planning conversations and finding out practical information.

Workshop series 2: Adapting GRACE for people with learning disability (LD) and dementia

Coproducers viewed the adaptation of booklets for people with a LD and dementia as an implementation strategy with potential to **increase reach**, extending high-quality post-diagnostic support to an underserved group. This gap was reflected by one participant, describing a forthcoming visit to a client with LD newly diagnosed:

“Going out next week..., they recently have been given a dementia diagnosis, I need to go through what is dementia, medication, practicalities. But not much out there for carers/ care homes. More on a diagnosis, now we need to know how we can help them.” [P9, professional]:

Another participant put this more starkly:

“historically people with learning disabilities have been underserved by all statutory services really... they tend to be the ‘Cinderella’ services” [P3, professional]

Reflecting this lack of available support, the group identified seven booklets requiring adaptation to be relevant for people with LD and dementia: (1) Getting Started, (2) Managing Physical Health, (3) Increasing Physical Activity, (4) Understanding Emotions, (5) Carer Wellbeing and Support, (6) Looking After Yourself, and (7) Enjoyable Activities.

Participants produced contextual knowledge by noting that framings discussing changes from a baseline of no cognitive difficulties did not fit people with LD, who often:

“Already at baseline have difficulties.” [P3, professional] and *“practically, LD already have a form of cognitive impairment... having to explain to someone that they have dementia, not easy for them to comprehend”* [P7, professional].

The group suggested revisions that shifted discussions from current abilities to *changes* in ability.

In Managing Physical Health, participants reported that people with LD and dementia often have:

“more physical comorbidities” [P8, professional], *“epilepsy is also very very common”* [L9, family carer with professional experience], and experience *“seizures definitely”* [P4, professional].

In response, the group proposed expanding facilitator notes to highlight frequent comorbidities in people with LD, and flag that activities involving physical activity (e.g., increasing mobility) may need adapting for people with LD:

“They have been in a residential home a long time, they are used to people doing things for them. It is difficult to get them up as they are already used to other people doing things” [P4, professional]

This pattern of identifying places where content may need to be adapted or facilitators prepared for discussions around different baseline functioning and associated health challenges extended across the remaining booklets. It was noted to also have benefits for people with other disabilities.

After the first co-production workshop's changes were implemented, participants noted the booklets still did not reflect people with LD and dementia:

"Images in activities booklet, full of pictures, didn't spot anyone with a disability." [L9, family carer with professional experience]

A workshop attendee shared a resource for sourcing inclusive imagery. This **co-produced contextual knowledge** directly informed revisions. We updated photos throughout the booklets to include people living with LD.

Participants also identified a need to ensure facilitator training was adequate to support people with LD. **Open, trustful and inclusive dialogue** allowed a person with LD to reflect candidly that professionals often lacked familiarity with the issues people with LD and dementia may face:

"Fully understand that people with learning disabilities have special needs. Haven't worked with people like me, don't understand what people with special needs are like." [L7, person with a learning disability]

A second participant with LD raised who should be directly consulted during GRACE sessions:

"Make sure asking me questions, not just going to my mum." [L8, person with a learning disability]

We used this **contextual knowledge**, to include a case study of working with a person with LD and dementia. Participants described the diversity of living and care arrangements for people with LD:

"50/50 divided group homes & supported living, younger people living with families." [P9, professional]

With one group home specialist support worker expressing that family input:

"Varies, some not involved, others more so, none as much as us" [P4, professional]

The group **worked collaboratively to generate meaning**, co-creating different solutions to how to GRACE might best support in these different contexts. The group reflected on how the interventions were tools that could be applied to different contexts, co-owned by the service providers using them, and no *"one size fits all"*. For workers within a group home who co-delivered care to a group of residents, GRACE-professional felt more of a good fit, while where one worker knew an individual resident especially well over a number of years, GRACE-family was suggested might work best:

"if you get services right for people with dementia you get services right for everybody and I think that's true for people with learning disability" [P3, professional]

Workshop series 3: Developing the GRACE professional for peer delivery within agencies

This workshop positioned **peer delivery as an implementation strategy with potential to increase reach**, reducing reliance on specialist facilitators and enabling delivery by staff who understood the realities of frontline care work.

Coproducers **developed contextual knowledge** around how to maximize acceptability of peer-to-peer learning to care workers. Attendees felt elements of the original intervention resembled workplace appraisal processes and felt too confrontative. Adapting activities that required personal disclosure, particularly in the earlier sessions, was viewed as particularly important when training was delivered by colleagues within the same agency. Discussions to co-create solutions reflected the development of **open trustful and inclusive dialogues**. One attendee's suggestion, the group decided to replace questions such as *"What skills do you bring?"* with broader, less personal prompts such as:

"What skills are important for a home care worker to have?" [P28, professional]

One attendee reflected that a *"more gentle tone"* was needed for peer-to-peer delivery, with activities encouraging discussion that did not feel overly exposing:

"What do your clients and their families appreciate about you?. Reframe to something like "What do you think customers of care would appreciate about good care?" [P36, professional]

Another consideration for peer-to-peer delivery was how to advise escalation when home care workers did not feel able to raise concerns with agency management. One manager suggested leaving a box where agency-specific escalation information can be added:

"Should carers disagree with their management, we signpost to e.g. local authority (would need to localize booklets), Care Workers Charity (offers free advice, counselling)." [P28, professional]

There was broad support for offering materials in multiple formats, including professionally produced paper workbooks, PDFs, mobile-friendly resources, and e-learning platforms. These discussions reflected **co-learning towards innovation** – with agency managers sharing the drives towards digital training and resources, while acknowledging that some agencies and care workers will still prefer hard copies.

"Make a PDF, more digital exchange: so paper and digital form (mobile phone friendly variant or as google forms format) could be good." [P28, professional]

These discussions resulted in a google classroom based digital version of the original pdf manual being designed by a professional digital design company: a direct result of **multi stakeholder collaborative action**.

Recognizing that home care staff often have limited time between sessions and a high work burden, one attendee recommended reducing written exercises and homework tasks:

"Depending on how far apart sessions are, homework might not be achieved. Change to a react and respond homework, such as thinking of an example where they reacted and how they would now decide to respond." [P36, professional]

The group suggested that reflective exercises were simplified and reframed to focus on how learning could be applied in practice. For example, participants proposed short reflective questions such as “What are three things I learned?” and “How can I implement them in my work?”

Some attendees commented on the mindfulness exercises, noting that they might not appeal to everyone. To address this, low-pressure reflective exercises/alternatives to mindfulness exercises (such as a spot the difference), assuggested by one attendee:

“Mindfulness/relaxation exercise – not everyone will engage. Good to have an alternative there too, such as a word search or colouring.” [P36, professional]

To “train the trainer”, there was a consensus that short role-play videos of intervention delivery would help demonstrate communication techniques and relationship-centered care:

“Preferred learning styles, videos can be quite powerful” [P36, professional]

Workshop series 4: Developing a tailored introductory session for people diagnosed in hospital

This workshop positioned the provision of better post-diagnostic support to people diagnosed in hospital as **an implementation strategy with potential to reduce care inequities**, and an opportunity to **reach** an underserved group with complex, intersectional needs. Two consultant physicians, who were interviewed together, reflected on this:

“I think given the fact that we both look after patients who are diagnosed with dementia as an inpatient, we have kind of noticed that there is a gap with kind of diagnostic care. So patients that can't come to memory services are particularly vulnerable They're the people that need the most support and having diagnosis in hospital. They sometimes fall through the gap and they don't get kind of post diagnostic care or follow up or support.” [P20, professional]

The attendees considered why some patients are admitted with undiagnosed dementia:

People that don't have good support networks, people that can't necessarily drive or you know, are not so much health seeking. They may not have GPs, they may not seen a GP for many years. [P20, professional]

Being diagnosed is harder in the context of severe mental illness, particularly if it's a language barrier.” [P10, professional]

They also commented on the need to design with this vulnerable population, and their intersectional needs in mind:

“And also I think I mean we deal with a very multi diverse complex population here in [place]. Making sure that that information is accessible in in different languages and at different kind of educational levels as well is is quite important.” [P20, professional]

Many aspects of GRACE were perceived to fit well with the needs of this group, such as the single point of contact (facilitator) to bridge between hospital and community:

“Adapting to hospital there are weeks where this sort of work could certainly start while they're inpatients if kind of the facilitators are able to visit the ward and coordinate with that, it doesn't maybe necessarily need to wait until they're discharged” [P15, professional]

Lived experience and practitioner attendees felt that use of the term “family carer” in the intervention should change to be more inclusive of the breadth of informal caring relationships:

“Could we change wording to person that is important to you instead of family carer; Could there be a live directory for post diagnosis care?” [L14, person living with dementia]

The group considered how to enable self-efficacy of the person with dementia, a key tenet of the intervention theory of change and a pertinent one in a setting that often felt disempowering. A lived experience member proposed the option of a page focused very directly on the person diagnosed with dementia, even where much of the intervention was primarily delivered to the family carer. He suggested some wording that the group used in the manual:

“your voice matters... It's about you and what you need.” [L14, person living with dementia]

This reinforced the group's emphasis on maintaining the voice of the person living with dementia whilst recognizing the important role of family members in shared goal-setting and decision-making.

The group considered together pragmatic solutions to making information relevant to the many different areas to which patients would be discharged. **Open, trustful dialogue** developed as clinicians and lived experience members shared frustrations at current lack of care integration:

“It's so disjointed, in xxx, there is a different set up and different support available – you wouldn't have everything in there. If you go to xxx this is what you may receive. As a clinician we had leaflets/website, services were constantly changing and service users would get upset at us if this information was not updated.” [P11, professional]

The group arrived at a solution, to: *“add boxes to the booklets, physically write these in a blank space so they are the most updated”* [P11, professional]

A major focus was around designing with comorbidities in mind. A practitioner reflected on how dementia diagnosis could be a shock when the focus of care, and admission is a different illness:

“something might be really seriously wrong physically and that dementia diagnosis is sort of tagged on to the diagnosis of pneumonia or whatever. Then they go home and they're making sense of it. Their loved ones are making sense of it. And there isn't necessarily that sort of transitional care. So people are left with a lot of anguish in the community and it feels as though there does need to be some sort of structured intervention to help those people to manage this new and life altering diagnosis.” [P10, professional]

At the second workshop, the group considered whether the possible goals areas covered could be more relevant to the population. Suggestions included:

"Feel more confident managing day-to-day health conditions after leaving the hospital" [L14, person living with dementia].

They proposed adapting the design to be clear that dyads could make a different goal that worked for them. While GRACE-family is intended and tailored to people with dementia living in their own homes, the group also acknowledged frequent uncertainty about place of discharge, and that the prospect of discharge could cause anxiety. They felt the new adaptation *would* work well this circumstance.

Attendees with caring experience considered hospitalisation as a particularly challenging time for family carers, a context which needed to be acknowledged in how support was provided:

"Carers can feel worthless or scared."

"It's really hard, if someone is a part of a couple, how do they maintain their relationship when someone is no longer a wife but a carer." [family carer, workshop 1]

Concern that the un-adapted intervention would feel overwhelming in this context, led to a key design decision, initially proposed by [L13, person living with dementia], to divide the existing first session into two, so a short first session could be delivered in hospital, acknowledging uncertainty of contexts and inviting dyads to explore as many ideas now as felt comfortable with the reassurance these topics would be revisited at the second session, most likely after discharge. An example of **multi-stakeholder collaborative action**, this gained traction in the wider group:

"Just if facilitators could acknowledge the shock and not feel as if they have to launch into these are the different types of dementia...reassurance that this is something that can keep being returned to" [P19, professional]

This tangible demonstration of the power of lived experience seemed to **generate meaning** for the group. A challenge from people diagnosed with dementia in the third workshop supporting development of resources for people diagnosed in hospital, informed co-adaptation group decisions around tailoring language to the person diagnosed with dementia:

"with the best will in the world if the carer is there, they will talk for them. Important person living with dementia is spoken with alone first. Who owns the goals? My husband could send completely different goals that I would want." [L17, person diagnosed with dementia]

This group proposed that:

"Language should be diagnosed person rather than lived with" [L15, person diagnosed with dementia].

The co-production group balanced the advice of this group that *“People with dementia need to be asked first”* [L17, person diagnosed with dementia] with goal setting with family carers being a core component of the effective intervention. They produced a version of the introductory session divided into two parts, so that people diagnosed with dementia could, where appropriate, be supported to explore possible goals alone, only bringing the dyad together in the second part.

When asked to review the final versions a PPI member living with a dementia diagnosis said:

“By including the person, carer and family throughout, the booklets are well managed well and any concerns can be effectively examined and explored by all involved.”

Workshop series 5:DevelopingGRACEfordifferent languages andan approach forlow literacy

At an early co-adaptation meeting, the group decided to focus on languages commonly spoken by older people within the areas in which initial GRACE implementation was planned - such as Punjabi, Sylheti, Hindi and Urdu, to maximise the reach this implementation strategy might enable. We planned the initial workshop to include people with expertise in these South Asian languages (including community leaders, interpreters and family carers of people with dementia).

The group came from a broad range of language backgrounds (Bengali, Punjabi, Hindi, Urdu speakers). They established **open,trustfuland inclusive dialogue** as they explored the complex task of language adaptation, considering impacts of generational, dialect, and different levels of dementia literacy:

“Hindi has changed for different generations. Hard to translate this” [P24, professional]

“Language can be quite complex I feel as we are all from different parts of the country. Each part has a different dialect which when spoken and written can differ from the main language which makes it complex. This can create difficulties while translation”.

[P24, professional]

The group discussed the importance of planning the use of language surrounding dementia carefully:

“When speaking about people with dementia who are elder, the language we use, the words and our way of speaking in the younger generations, everyday language can be quite difficult for the elderly to understand”.
[L2, family carer]

Through these discussions, the group generated and used **contextual knowledge** to decide on the languages to translate to (the programme was funded with an intention to create two new language versions) *“based off the local community, that had a high proportion of people that speak Sylheti/Bengali”*. Based on the relative homogeneity of how they were written and spoken across cultures, the group decided on Urdu and Hindi, noting that Punjabi had *“many different dialects”* so no one version would suit all Punjabi speakers in the UK.

The discussion around ways to adapt the intervention to make it more accessible to people using the new language versions was an example of **co-learning towards innovation**:

"Because I know what's the meaning of '----', but other people might not know what you mean by that". [L11, lived experience]

The facilitators asked the group what instructions they might give to professional translators creating the new versions. Community members warned that standard translation in Hindi or Urdu could produce *"Shakespearean English"* [L2, family carer]. One interpreter suggested asking for *"simple everyday language"* [P24, professional]

The group agreed **multi stakeholder collaborative action**: they agreed instructions they would give to a professional interpreter service, and that Hindi/Urdu speakers from the group would review the first session once translated (and discuss at a follow-up workshop), before proceeding with the full translation.

The group also developed plans for maximising inclusivity when the intervention was delivered using an interpreter for another language, by *"making a recording of the booklet instead"* [P26, professional]. They reflected on how such an approach could work well for people with low literacy from all linguistic backgrounds.

"So anyone who can't actually physically read it, they can just listen to the recording, which we feel like will increase accessibility". [P26, professional]

Another member proposed *"inviting the participants to record sessions on their phones"*. The group considered that as smart phones now commonly enable this, it would allow participants to keep control of their own session recording, increasing trust.

The group discussed how such an approach could avoid the embarrassment and stigma people with low literacy may experience asking for this, *"by increasing accessibility"*, by offering it to everyone as standard; as this is an option that many may wish to take up regardless of their literacy levels, *"so anyone who can't physically read it, they can just listen"*.

The final co-production workshop provided an opportunity for participants to review the first translated materials and assess whether any of the suggested recommendations from the initial language co-production workshop had been successfully implemented before progressing any further. The first Hindi translation was translated, using AI-assisted translation following extensive review by bilingual members of the research team. Participants welcomed the inclusion of a glossary to explain terms without direct translations and suggested making the language of each booklet more prominent to support facilitators:

"It might be worth adding what language the booklet is.. might be easier to pick up something as a facilitator to give the correct booklet to participants" [L2, family carer].

The discussions reinforced the group's earlier recommendation that translations should prioritise conversational, everyday language rather than literal translation. While participants felt the Hindi version reflected this approach, they identified that the professionally translated Urdu version relied on highly formal language that would be inaccessible to many community members:

"If I was to talk to my clientele, for example your average Mrs X may not have that level of education" [L2, family carer].

They reflected that translation services were helpful in conversational translations but would often use language that is *"more academic"*, explaining that *"if an average everyday person cannot understand the academic version, then it is just like the English version"* [L2, family carer].

Following discussions from the previous workshop, participants emphasised the importance of making materials accessible for people with low literacy. One participant [L11, family carer] suggested replacing individual recordings with QR codes linked to audio versions of the booklets, explaining that *"a lot of people can't read it, they understand it"*, others also highlighted recognising the differences between spoken and written language across communities. Reflecting on Bengali-speaking communities, one participant explained that *"more educated"* [P26, professional] people would be able to read standard Bangla, whereas many others would benefit from audio delivered in the Sylheti dialect.

The workshop also extended on previous discussions concerning the use of interpreters, emphasising that interpreters should assist in core understanding rather than providing literal translation. As one interpreter explained, the *"job goes beyond... need to ensure they have an understanding"* [P24, professional], highlighting that direct translation alone was often insufficient for expressing a word in its equivalent with another attendee stating *".. Realised there was no translation, so it is helpful to know it cannot be, spend less time on that, use the English and then spend more time explaining.."* [P27, professional]. Participants agreed that interpreters should be briefed before each session so they understood the purpose of the intervention, participant background, and key terminology, allowing them to provide culturally meaningful explanations where required:

"More free conversations, to ensure the message is being explained in the right way. Person having the interview can fully understand" [P27, professional].

The meeting concluded with agreement that all translated materials would undergo further review by community members before pilot implementation. One facilitator reflected, *"the whole point is we want to be increasing access to people who usually miss out due to language"*, demonstrating the value of the co-production process enabling the intervention to become progressively more accessible, culturally relevant, and reflective to community needs.

Figures

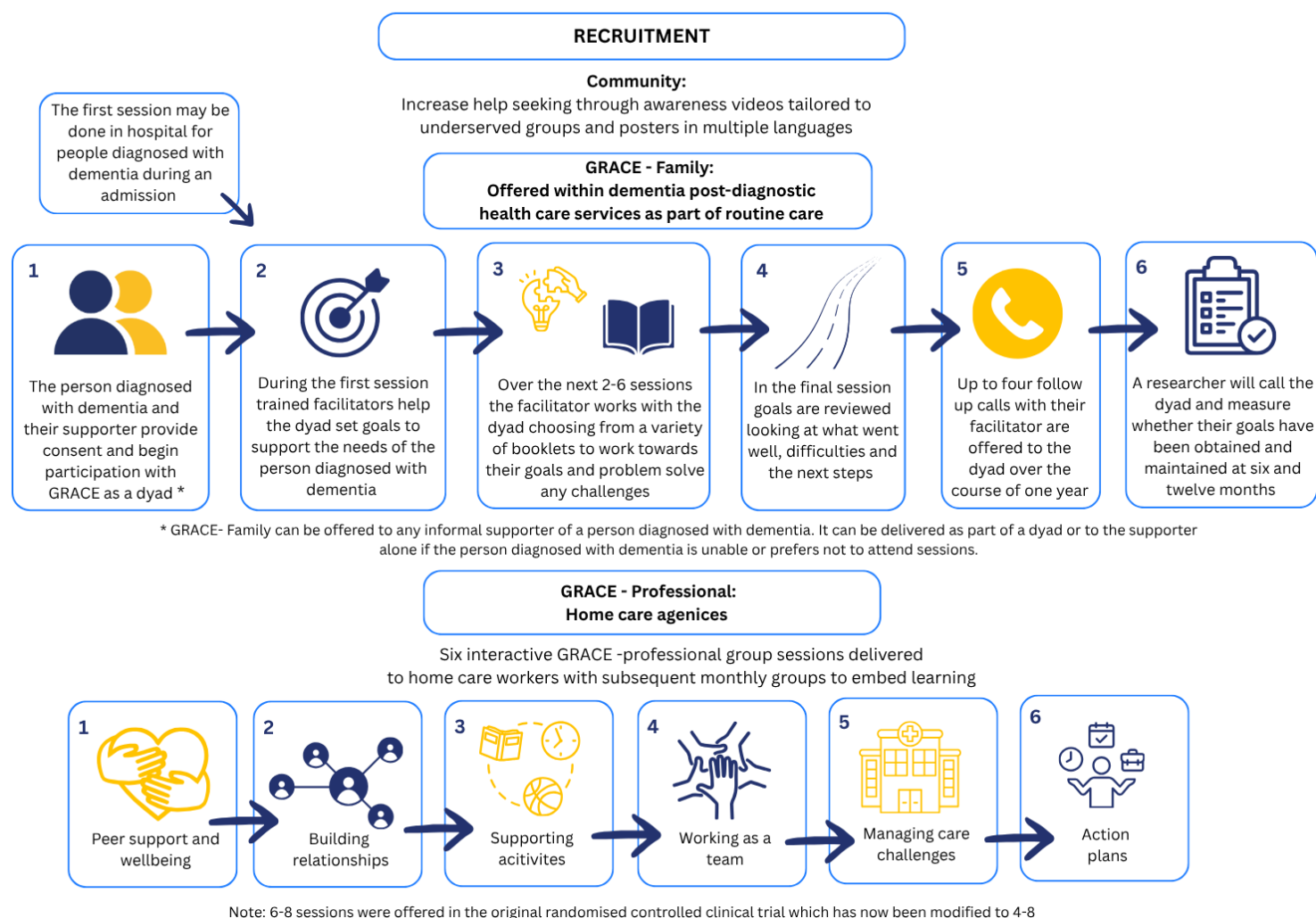


Figure 1

The GRACE intervention

Framework elements

GRACE Programme



*Baumann, A. A., & Cabassa, L. J. (2020). Reframing implementation science to address inequities in healthcare delivery. BMC health services research, 20(1), 190. <https://doi.org/10.1186/s12913-020-4975-3>
 Framework modified and adapted by the GRACE team.

Figure 2

GRACE programme alignment with an implementation science framework to study care inequities*

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [GRIPP2shortform.docx](#)