



UWL REPOSITORY

repository.uwl.ac.uk

Role of peer-tutors with dementia in Recovery College dementia courses: an ethnographic account

Burt, Linda, Handley, Melanie, West, Juniper, Alam, Jarin, Poland, Fiona, Moniz-Cook, Esme, Wolverson, Emma, Wong, Geff, Hackman, Corinna, Teague, Bonnie, Literland, Rachel and Fox, Chris (2026) Role of peer-tutors with dementia in Recovery College dementia courses: an ethnographic account. *The Gerontologist*.

<https://doi.org/10.1093/geront/gnag010>

This is the Accepted Version of the final output.

UWL repository link: <https://repository.uwl.ac.uk/id/eprint/14514/>

Alternative formats: If you require this document in an alternative format, please contact: open.research@uwl.ac.uk

Copyright:

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy: If you believe that this document breaches copyright, please contact us at open.research@uwl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Rights Retention Statement:

For the purpose of open access, the author has granted their employer, the University of West London, a non-exclusive, irrevocable, sub-licensable, worldwide license (effective from acceptance of publication) to make any final accepted manuscript publicly available under the terms of a Creative Commons Attribution (CC-BY copyright) license. Please direct any correspondence to open.research@uwl.ac.uk

Role of peer-tutors with dementia in Recovery College dementia courses: an ethnographic account

Linda Birt^{1,2} PhD, School of Healthcare University of Leicester, UK.

 <https://orcid.org/0000-0002-4527-4414> CORRESPONDING Author

Melanie Handley³ PhD, Centre for Research in Public Health & Community Care, University of Hertfordshire, Hatfield, UK  <https://orcid.org/0000-0002-8037-5042>

Juniper West⁴ MSc, Research and Development, Norfolk and Suffolk NHS Foundation Trust, Norwich, UK  <https://orcid.org/0000-0003-0802-7243>

Jarin Alam⁴ MSc Research and Development, Norfolk and Suffolk NHS Foundation Trust, Norwich, UK  <https://orcid.org/0009-0007-3135-6260>

Fiona Poland² PhD  <https://orcid.org/0000-0003-0003-6911>

Esme Moniz-Cook⁵ PhD, Faculty of Health Sciences, University of Hull, UK  <https://orcid.org/0000-0002-7232-4632>

Emma Wolverson^{6,7} D Clin Psych Geller Institute of Ageing and Memory, University of West London, London, UK + Research and Publications, Dementia UK, London, UK  <https://orcid.org/0000-0002-5789-7862>

Geoff Wong⁸ MD (Res) Nuffield Department of Primary Care Health Sciences, University of Oxford, UK  <https://orcid.org/0000-0002-5384-4157>

Corinna Hackmann^{4,9} PhD Research and Development, Norfolk and Suffolk NHS Foundation Trust, Norwich, UK  <https://orcid.org/0000-0002-4940-6998>

Bonnie Teague^{4,10} Research and Development, Norfolk and Suffolk NHS Foundation Trust, Norwich, UK PhD Department of Clinical Psychological and Psychological Sciences, University of East Anglia, Norwich, UK  <https://orcid.org/0000-0002-3248-2257>

Rachael Litherland¹¹ MSc Innovations in Dementia CIC, Exeter, UK  <https://orcid.org/0009-0003-9747-6207>

Christopher Fox¹² MD (Psychiatry Dementia) Medical School, University of Exeter +³  <https://orcid.org/0000-0001-9480-5704> on behalf of the DiSCOVERY study team.

Corresponding author

Dr Linda Birt, School of Healthcare, University of Leicester, England, LE1 7RH

Linda.birt@leicester.ac.uk

Role of peer-tutors with dementia in Recovery College dementia courses: an ethnographic account

Abstract

Background and objectives

Receiving a diagnosis of dementia impacts life plans and can lead to feelings of hopelessness and social disengagement. Post-diagnostic support can help people adjust to and assimilate a changing identity. Recovery Colleges in the UK offer a specific form of post-diagnostic peer-led support. This paper aims to provide a rich account of 'stand out' moments where the key tenets of recovery-focused post-diagnostic support were enacted.

Research design and methods

Using ethnographic observations and interview data from the *anonymized Study*, a realist evaluation of Recovery College dementia courses, we examined data to specify activities of peer-tutors and the mechanisms which shaped outcomes for people with dementia.

Results

Five Recovery College dementia courses were observed across four NHS mental health services in England. Post-course interviews were undertaken with 13 tutors (3 peer-tutors with dementia) and 32 attendees (8 people with dementia). We found that through co-facilitation of recovery-focused content by peer-tutors who have well developed facilitation skills, attendees appeared to mediate self-stigma, manage emotional uncertainty and make meaningful social connections in ways which engendered hope for their future.

Discussion and implications

Identifying the activity between peer-tutors with dementia and course attendees foregrounds key strengths and limitations of this distinctive form of post-diagnostic support. Future work should evaluate longer term outcomes for people with dementia attending recovery courses before potentially expanding this form of post-diagnostic support.

Keywords: dementia, identity, co-production, peer support, safe uncertainty, stigma, hope, realist evaluation.

BACKGROUND AND OBJECTIVES

Being diagnosed with dementia has a life-changing impact on a person and their family. People may need to adjust to and potentially assimilate a changed identity as a person with dementia (Birt et al., 2017). There is no cure and newly-licensed medicines have limited effect (Walsh et al., 2024). Numbers of people with dementia increasing globally (Wittenburg et al., 2019) and within the UK National Health Service (NHS) referral rates to diagnosis in memory services is expanding meaning there is urgent need to provide sustainable post-diagnostic support. Sustainability in this context is defined as: “... *patient-centred, focused on recovery, self-monitoring and independent living, and actively reduces the need for intervention.*” (Jethwa et al., 2024 p5). The period immediately following diagnosis is critical in enabling people to maintain a non-stigmatised social ‘self’ (Birt et al., 2020) and to build personal resilience (Windle et al., 2023) for coping with the combined psychological, physical, social and emotional effects of this progressive and life limiting diagnosis (Watts et al., 2014).

Peer-led education offers ways for people to actively adapt and problem-solve to live positively with dementia (Bamford et al., 2021; Jopling, 2017). UK policy identifies key areas for improving the quality of post-diagnostic support, including shifting focus to ‘living well’ with long-term conditions. A national strategy promoted dementia peer-support and learning networks, specifying an objective to empower people with dementia to make their own choices in future planning (Department of Health, 2009). This vision contrasts with lived experience reports of post-diagnostic support disempowering individuals, defined as Prescribed Disengagement™ (Low et al., 2018). Dementia peer-support initiatives are commonly available world-wide, they are often community-led and as such, may provide support but will not necessarily specifically enable self-reflection, learning and empowerment. Finding ways for people with dementia to activate their personal strengths and build positive relationships is especially important as there are variable levels of statutory post-diagnostic support (Dooley et al., 2025).

Peer support through Recovery Colleges

Recovery Colleges are an international initiative to help people assimilate mental health diagnoses on their own terms and learn ways to live positively with their symptoms (Leamy et al., 2011). The delivery of psychoeducation and adult learning is premised on co-production between people with lived experience and health professionals. Courses focus on personal recovery, informed by the ‘CHIME’ framework tenets: Connection, Hope and optimism, Identity, Meaning and purpose, and Empowerment (Leamy et al., 2011). Where and how Recovery College courses are provided differ, but in the UK, many align with and complement statutory mental health services (see Supplementary File 1). Importantly, the Recovery College provides flexible access to psychoeducation, peer-support and knowledge sharing from lived experiences in the post-diagnosis period. Courses are generally open access enabling people with lived experience, family or friend supporters

and healthcare staff to self-enrol without having to go through a referral system (Perkins et al., 2012). While the term recovery may be at odds with the reality of an illness that reduces life span and quality of life, in this post-diagnosis setting it is used in the context of making sense of what happened (here in the diagnosis) and finding new ways to live a meaningful life with the illness (Perkins et al. 2012).

Recovery Colleges and dementia

Courses specifically designed by and for people with dementia and their supporters are being added to the Recovery College offer. Nonetheless such courses are not available in all NHS mental health services (Lowen et al., 2019), and when they are, staff involved in diagnostic services often do not routinely signpost newly-diagnosed people to Recovery Colleges (Wolverson et al., 2024). Where dementia courses are provided the co-production and co-delivery between staff and people with lived experience is considered important to personal recovery from a dementia diagnosis (Kenny et al., 2016; West et al., 2022). However, there is limited empirical evaluation, including of the causal mechanisms underlying this. A realist review reporting on Recovery College dementia courses led to initial programme theories on aspects relating to co-producing courses (Handley et al., 2024). The review results emphasized the need for: co-production; tackling stigma; embedding of personal recovery principles; and the importance of providing practical and emotional support to ensure people adjusting to a diagnosis of dementia can access and benefit from the courses (Handley et al., 2024). However, the review found little evidence on the experiences of those who attended these dementia courses.

RESEARCH DESIGN AND METHODS

In the DiSCOVERY Study we conducted a realist evaluation of English mental health service delivered Recovery College courses using a case study design (Birt et al., 2023). Realist evaluation is used to identify programme theories explaining how interventions are thought to work for various stakeholders by formulating evidence-based programme theories. These theories set out how relationships between the underlying mechanisms and contextual factors lead to different outcomes (Pawson & Tilley, 1997).

Important in realist approaches is a detailed understanding of context. Context may be shaped by organization policies and rules, but is also impacted by cultural concepts such as intersubjective beliefs, norms and values. Collecting data through a focused ethnography, using a case study design, enables examination of cultural factors at play (Jones-Hooker & Tyndall, 2023).

This paper draws on data from ethnographic observations and realist interviews with tutors and attendees who had dementia. However, given that courses took place in group settings, where interactions observed could be supportive or dismissive, we also draw on relevant data from family supporters and staff attendees to specifically examine and define key outcomes for people with dementia in co-producing, facilitating and attending Recovery College dementia courses.

Study aim

The realist evaluation aimed to define '*what works for whom, in what circumstances, and why*', in Recovery College dementia courses, specifically focusing on outcomes relating to post-diagnostic adjustment. Results on how the evaluation refined initial programme theories developed during our realist review is published elsewhere (Birt et al., 2025). This paper has a specific focus on how people with dementia, either in a peer-tutor role or as an attendee, experience Recovery College dementia courses and discusses observed and reported outcomes.

Ethical approval

Ethical approval was granted by Coventry & Warwickshire Research Ethics Committee (22/WM/0215). This work is part of the DiSCOVERY research programme (reference NIHR131676, 2022-2024). Full protocol details are available at Birt et al. (2023). A person with dementia from the DiSCOVERY Partners in Research group attended the ethics committee review meeting alongside researchers.

Recruitment and sample

Recovery Colleges within English statutory mental health services offering dementia courses were approached. Inclusion criteria were: a) staff, people with dementia, family supporters either co-producing material and/or co-facilitating courses; and b) course attendees - predominantly people with dementia and family supporters but also health and social care staff and members of a Recovery College. Purposive sampling enabled us to recruit courses from diverse geographical locations that had a variety of delivery styles. We sent study information to each site and held discussions before seeking consent from potential participants. In each case, staff and peer-tutors gave written consent to the course being observed. Recovery College staff sent study information to people enrolled on the course at least 48 hours before and course attendees were advised researchers would be present. Attendees' consent was secured before the course started; all people with dementia were able to give informed consent. Tutors and attendees were informed of the opportunity to take part in a post-observation interview for which we obtained their additional consent. Recovery College staff and dementia service managers were also offered an interview.

Data collection

Focused ethnography

Two of three female researchers (LB, MH, JW) observed each course; all had extensive experience of research with people with dementia. Observations aligned with ethnographic methods using short, focused field visits (Wall, 2015). At times researchers joined in activities such as icebreakers, but mostly they sat amongst the attendees discreetly observing and recording activities. A formal template was not used but notes recorded the setting, actors, materials shared, who led discussions, tutors and attendees' reactions to materials, chat between actors and changes in attendees' demeanour or involvement. Following each session, researchers debriefed and reflected together.

Realist interviews

Tutors and attendees were offered individual interviews following the courses; either virtual or in-person. Topic guides (see Supplementary File 2) were developed with stakeholder advisory groups (Manzano, 2016) drawing on findings from the realist review (Handley et al., 2024). Interviews served the dual purpose of understanding individual experiences of Recovery College dementia courses and testing initial theories of what worked and why.

Data analysis

Data were pseudonymized. Interviews transcribed verbatim from digital recording and identifiers removed to maintain anonymity. Handwritten field notes were typed up and a single document agreed for analysis; reflective memos were maintained. Data were managed in NVivo (QSR International, 2020) and analyzed using realist logic (Pawson & Tilley, 1997). Coding was deductive (informed by the review's initial programme theories); inductive (derived from the collected data); and retroductive (inferences about mechanisms based on interpretations of data about underlying causal processes). LB, MH, and JW then independently revisited coded data on NVivo to develop Context-Mechanism-Outcome-configurations (CMOCs) which set out causal explanations of what works, for whom, when and how. Twenty CMOCs were grouped to the key concepts they represented (see Supplementary File 3).

An important step in realist evaluation is to consider formal (or substantive) theories which provide underpinning explanations for how mechanisms work in specific contexts to lead to outcomes. The conceptual personal-recovery CHIME framework (Leamy et al., 2011) and theories underpinning a person-centered approach to dementia (Downs & Lord, 2017) were identified. Research team meetings identified further conceptual models that explain the value of collaborative and interactive processes in Recovery College dementia courses. These included theories of hope (Dufault & Martocchi, 1985) and how people with dementia create meaning in everyday social interactions (Kitwood, 1997).

Advisory groups

Developing results were structured into pre-reading discussion papers and slide sets by LB and JW, to enable systematic deliberations with the Partners in Research advisory group (people with dementia) and Staff stakeholder groups, and the wider research team. This iterative process of data analysis continued at regular intervals throughout the 18-month data collection period. Data was enriched with reflections from those stakeholders who gave consent to recording of meetings and use of illustrative quotes. Meeting transcripts were date-stamped, reviewed and advisory group statements validating or contesting researcher interpretations were highlighted. Specifically, the experiences of the Partners in Research group related to co-producing and attending similar 'living with dementia' courses providing triangulation of the empirical data set.

RESULTS

Sample

Five recovery-focused dementia courses were observed in four NHS Mental Health Trusts. Four courses were fully embedded within their Recovery Colleges. A fifth course, although originally developed within the Recovery College, was now being delivered as part of NHS post-diagnostic provision. Twenty-three people with dementia were observed and of those, 11 (3 peer tutors (2 Female); 8 Attendees (7 Female)) were interviewed across the 5 case studies (see Table 1 for sample details). To protect site and participant anonymity, we use minimal detail to refer to participants. This level of anonymity is used as few Recovery Colleges are currently running so if personal characteristics were provided as well as method of delivery, the case site might be identified. There was representation of gender and age across the sample, but limited ethnic diversity.

Insert Table 1 *Sample characteristics*

Three thematic areas describe critical ‘stand out’ moments which present how context shapes outcomes for attendees with dementia: 1) Empowering and enabling non-stigmatized identities, 2) Managing uncertainty for positive reframing; 3) Connecting together enabling hope. We present results by providing illustrative examples from observation data, supplemented with interview data, alongside interpretations of the context and mechanisms at play.

Findings

Theme 1 Empowering and enabling non-stigmatized identities

Insert Figure 1 here

An essential component in Recovery College courses is co-production and co-facilitation by peer-tutors with lived experience. The four courses where a peer-tutor with dementia actively co-facilitated, powerfully depicted when the actions of peer-tutors with dementia appeared to enable attendees with dementia to experience positive connections, and importantly to also be seen by others as persons beyond their dementia designation. Essential to inclusivity of course delivery was peer-tutors being ‘one of the group’, more closely aligned with attendees with dementia than with staff. This happened when the peer-tutor clearly led the course, with the staff tutor merely prompting or helping to keep to time. In all in-person courses the peer-tutor at some stage positioned themselves physically with the attendees, and in one course the peer-tutor with dementia sat in the circle amongst attendees.

A ‘stand out’ moment occurred during an in-person, 2-hour single session course (Case D). The course was

facilitated by a staff tutor and a peer-tutor with dementia; the peer-tutor predominantly led all activities with small prompts from the staff tutor. In this session all information was shared verbally, unlike other sessions where there were powerpoint slides, handouts and sometimes writing activities. Attendees included staff, family supporters, and several dyads (person with dementia and family supporter). The peer-tutor, who had early onset dementia, recounted their traumatic experiences of diagnosis, and ways in which they now live their life more positively. This included how they maintain social connections, get involved in research and find purpose and meaning in everyday activities such as going for walks. Towards the session end, the staff tutor asks attendees to share experiences and for questions. Both tutors are sitting at the front of the room and chairs are set out in 5 rows with a central gap to walk down. Our observation fieldnotes capture ways in which the peer-tutor empowers an attendee with dementia to have a voice within a large and unfamiliar group of people.

Observation Extract 1:

A person with dementia sitting in the back row next to his spouse starts to speak, he lifts a hand up, hesitantly stumbling to get words out... *"happy with you speech, can't speak and I want to speak"* relating to what the peer-tutor with dementia is saying. The peer-tutor speaks directly to him and validates his experience; *"It's frustrating, it is never easy"*. The attendee's speech grows stronger as the peer-tutor nods towards him, and the attendee says, *"that's exactly what I'm feeling, yes"*. The peer-tutor stands and moves forward into the gap between the rows of chairs to speak directly to the attendee, who then talks a bit about his previous occupation, *"used to work on a drawing board"*. His family supporter joins in to say the attendee might be embarrassed about his disabilities caused by dementia. The peer-tutor moves further forward and their one-to-one exchange continues, encouraged and reassured by the peer-tutor who says *"you put together the most wonderful sentence, don't stop," "thank you for sharing"* and *"this is a very touching moment"*. Despite the direct interaction, the peer-tutor is simultaneously inclusive of everyone in the room by looking around and using physical presence to draw everyone in to the exchange, getting nods and murmurs of agreement from others. They conclude that people with dementia need more time to process and speak in each moment.

This extract demonstrates how important specific actions can be in promoting a non-stigmatized identity and /or felt sense of self for people with dementia. The actions that created the context (outlined in the overarching CMOC above) were the peer-tutor's observation of the room which led them to notice a peer struggling to speak and raising their hand; the peer-tutor used active positioning to bring others into what was, in effect, a one-to-one interaction. The outcome was the attendee with dementia positioned himself as a person

by occupation, here describing his employment. A wider outcome was learning for others in the room about the importance of giving people with dementia time and attention to speak. On interviewing the peer-tutor with dementia afterwards, they reflected on this interaction: “... *but he put together this amazing sentence that just shows how, if people are in that environment where they feel safe, they can do more than they think they can. It just relaxes them into, for him, speech. ... I mean, we have [standout moments] every time with peer support, but to have it happen with a stranger, it’s always just a magic moment.*” These may be examples of transformative learning (Oh, 2013).

By providing examples of living positively, peer-tutors with dementia appeared to help attendees to have hope and consider themselves in more valued ways, thereby potentially reducing self-stigma. The input from peer-tutors across all courses appeared to help family supporters and other attendees to consider people with dementia in non-stigmatizing ways. However, there were occasions where peer tutors who were family supporters, talked of their experiences in ways that position the care of a person with dementia as burdensome.

In telling their experiences peer-tutors relived stigmatizing experiences and it was important they were empowered to have control over what they shared and when. Here in a post-session interview from Case A, the family supporter provides context to an event where the peer-tutor tells of sharing her diagnosis with a long-standing social group.

Observation and Interview Extract 2:

Peer-tutor daughter: Yeah, you do sometimes in [*share the experience of telling friends*] some of the sessions, but not every session. So, I would say that when mum feels OK to share that she does and other times she doesn’t. (observation noted daughter looked to mother and checked she alright to tell story)

Peer-tutor female with dementia: It’s a very difficult thing. They’d all just come back from a group outing and I’d got to tell them because I couldn’t just stand there because they were saying, “How are you?” I had to say, “I’ve got dementia.” There was everyone looking at everybody else and so in the end I just said, “Well we’ll go now then.”

Interviewer to peer-tutor: Yeah, so it sounds like each session, there is no script, you don’t always say the same thing, it’s whatever you feel is the right thing at that time.

Peer-tutor with dementia: Yes.

Here we see the family supporter’s work in creating safe spaces for people with dementia either as peer-tutors or attendees to revisit and share previous stigmatising events. When peer-tutors shared their diagnosis experience, attendees nodded as if agreeing and recognising their experience was not unique nor stigmatising.

Theme 2 Managing uncertainty for positive reframing

Insert Figure 2 here

People usually attend Recovery College courses within a few months of diagnosis, meaning emotion and shock from receiving their diagnosis can still be raw. This can lead to people becoming distressed during the course. While staff tutors will usually be able to draw on clinical training to support an attendee who is emotionally upset, peer-tutors often do not have formal training for this. This 'stand-out' moment illustrates both the empathy peer-tutors can display with others' lived experiences, and the skills they can adopt to contain upsetting emotions in others.

The course was in-person and a single 2.5-hour session (Case C). The setting was a meeting room in a building used by the mental health service. The course was facilitated by a staff tutor and two peer-tutors: a person with dementia and a family supporter. There were 10 attendees: people with dementia attending alone, family supporters attending alone, 2 dyads (person with dementia and family or friend supporter) and a staff attendee. Attendees heard about the course mainly from their clinician who was the staff tutor, but a couple had heard from other community groups including the attendee who was distressed. Before the course started a person with dementia, attending alone, was visibly distressed, attendees waited with some hesitant anticipation for the course to start, a few people talking to each other. The extract below describes the situation approximately 10 minutes into the course; the group had introduced themselves by stating they had dementia or were a family or friend supporter.

Observation Extract 3:

Everyone is sitting around a large central table which means people can have eye contact. The attendee shows small signs of anxiety through worried facial expression. She then becomes distressed and tearful, self-blaming for having dementia. Everyone stops and listens and the peer-tutor with dementia responds and offers reassurances. Following the exchange, the staff tutor takes a seat near to the computer for presenting slides and indicates non-verbally to the support staff member to move to the empty chair next to the person. A group activity is facilitated where peer-tutors hand round a wellbeing questionnaire for attendees to chat through together and complete. There are high levels of engagement by all with 'ad hoc' questions being asked about dementia, and some laughing and joking. The attendee again becomes tearful while talking of a traumatic experience, the peer-tutor with dementia takes over from the staff member sitting next to the person. They speak quietly and supportively and the attendee visibly calms. Following slides about

the ageing brain, the staff tutor sets the scene for a further interactive activity, by asking *“What is your understanding of what it is like to have dementia? What images come to mind?”* The peer-tutor with dementia gets up; *“Let’s write some of these down”* and moves to a flipchart. The attendee again becomes distressed *“It’s my fault I’ve got it [dementia]. I blame myself”*. The staff tutor asks the person and the group to focus on dementia symptoms *“what sorts of symptoms do you have?”*. Attendees including the distressed attendee offer words such as ‘forgetfulness’ and the peer-tutor family support writes them on the flipchart, the peer-tutor with dementia talks about his own experience to keep the group joining in.

This example provides evidence of both the staff and peer-tutor being aware of others' emotions and having skills and being prepared to work together to manage emotions. For example, here the staff tutor indicates for someone to sit next to the attendee and shifts the focus onto symptoms rather than causes. The peer-tutor with dementia showed awareness of the attendees' struggle; and had the confidence to support with quiet interaction. The attendee is able to contain their distress, and the rest of the group can relax. The mechanism found to help resolve this situation appears to be the ability of tutors to create a space of psychological security, where a range of emotions can be acknowledged rather than dismissed. In the post-course interview, we spoke to the peer-tutor with dementia about the attendee's distress and how the situation was managed. The peer-tutor explained they helped the attendee contain their emotion: *“I was worried. When the lady who presented with the very emotional, tearful response at the beginning, you know, she was on the verge of it being appropriate to remove her from there to somewhere quiet for a one-to-one chat.”* They go on to explain that if the staff tutor left the room this would leave the peer-tutors uncertain about what to do: *“I don’t know how I would’ve coped with that because the only person at the moment who is competent to deliver the rest of that presentation is the practitioner [staff tutor].* This highlights a challenge for delivering courses if only one or two people have the knowledge or skills to facilitate. Finally, the peer-tutor confides that the situation felt like a ‘small pressure cooker room’ where ‘hysteria could have taken over in the room’. Importantly, because all tutors were able to effectively help the attendee ‘hold’ their emotion, the person was calm enough to attend to the information being shared by the staff tutor on the potential causes of dementia, and later she is heard to say *‘I don’t need to blame myself’*.

Further into the session the peer-tutor with dementia leads a section creating opportunities for the attendee with dementia to share positive aspects of herself beyond dementia.

Observation Extract 4:

The staff tutor asks the peer-tutor with dementia to discuss their experiences he engages the group, they are all listening. When speaking of their fundraising the previously distressed attendee with dementia chips in that she

joined the fundraising walk. The peer-tutor passes pictures round of things they have done, there is some laughter as they talk. The peer-tutor describes being able to use 'dementia goggles'; *"You are valuable as consultants"*. The attendee with dementia says *'you feel wanted'* there is a visible change in her facial expression and body language appears more upright and smiling, *'you meet people who make you laugh'*. This stand-out moment demonstrates the value of having peer-tutors with lived experience of dementia who have empathy with emotional responses, but also demonstrate ways in which they have managed the uncertainty of dementia themselves.

Theme 3 Connecting together enabling hope

Insert Figure 3 here

While a person with dementia may attend a Recovery College course alone, we observed more people attending as a dyad with a spouse, adult child or friend supporter. During in-person courses peer-tutors created content and time for dyads to undertake activities together, prompting connections in a neutral and potentially 'safe place' away from usual home life. In case A all attended as a partner/spousal dyad; each dyad discussed between themselves what made them feel stressed. We noted phrases such as *"when you rush me to go out I feel stressed and anxious"*. We observed when activities asked dyads to work together, staff and peer-tutors often moved to be physically present with the dyad and to support conversations between individuals. Sometimes the format of the Recovery College course led to new understandings between relatives. In this stand-out moment during an in person single 2.5-hour course (Case C), the relationship history between the person with dementia and the adult-child was difficult; a daughter family supporter considered their mother to be in denial of their diagnosis, as they had never spoken about having dementia.

Observation and interview Extract 5:

Once everyone had settled, the staff tutor stood at the front of the room, welcomed everyone to the session and invited round table introductions. Everyone used the word 'dementia' during their introduction although there was no stated prerequisite for this. Each person said why they were there, and the mother of one child/parent dyad clearly said three words *"I have dementia"*, at which the daughter showed complete surprise.

The daughter later explained during an interview how this incident enabled her to understand more of her parent's experience and to begin to know how her mother felt about their diagnosis: *"It was the first time my mum had actually said that she had dementia there. ... She'd not said it before, no. ... That was the first time and she actually said those words and I was like, 'Oh God, I can't believe it.' ... I was really surprised and it made me feel quite emotional. You know, I could have easily burst into tears. ... and it probably made me feel more*

connected to her because it's difficult to be close to my mum".

The context of a group expectation that the person will identify themselves can be viewed in two ways. It may be interpreted as a non-judgmental space within the Recovery College course that enabled a person with dementia to verbally acknowledge their dementia diagnosis in front of their relative. However, it could be seen as removing the right of the person with dementia to avoid discussing their diagnosis with family. While the daughter found it cathartic, the follow up interview with the mother was very brief and it appears the decision to attend was not fully her own, *"I don't know, my daughter said she'd take me. I would meet other people"*. We do not have data on how comfortable she was with saying she had dementia.

In some courses we observed delivery of material being tutor-led with limited space or activities for attendees to connect. Factors like the setting and method of course delivery affected whether people had the time and physical space to connect formally or informally. For example, being in a warm and welcoming setting with space for coffee breaks and movement meant people interacted more. Here a peer-tutor with dementia who delivered courses both online and in person (Case D) explains the importance of such breaks for socially connecting and information sharing:

Interview Extract 6:

Peer-tutor with dementia: *Also it may be a bit of a bizarre thing but you'd miss the coffee breaks [online] and we have really good conversations in coffee breaks. We will find out, we'll talk to people and people are open and much more likely to say something that's concerning them or something they might think it's silly and don't want to say in front of anyone else. All sorts of things have come out of previous groups in the coffee break haven't they. We'll talk about all sorts with people and you'd miss that.*

In courses run in-person across several sessions we observed interactions between attendees and peer-tutors increasing over time. Coffee breaks and food sharing led to an attendee with dementia striking up conversation and sharing recipes with another attendee. The person with dementia was thus enabled to present themselves as a cake-baker and to discover shared interests with an attendee who was a stranger, socially connecting and empowering conversations beyond having a dementia diagnosis. Nonetheless there was an absence of culturally diverse social activities presented or discussed. A family supporter spoke of her exasperation at finding appropriate community activities for her mother, born in the Caribbean, who came to the UK as an adult. *"We searched for things that she could do, but we live a predominantly white area. I contacted the services just to find out what if there is anything that's specifically for Afro-Caribbean people. I think there's ... but it's in the daytime and I don't even know if it's still running. I don't think the [recovery] course is set up to even address it."*

We saw activities creating safe spaces for people with dementia to join in without fear of failure or

need to share or explain their dementia. In warm up activities prefaced with *'tell us why you are here?'* people usually stated their dementia status or supporter, or staff role. This created a status divide. In one course the peer-tutor suggested a more inclusive warm-up: people were asked if they were a dog or cat person. The activity was introduced using slides with images of cats and dogs and the peer-tutor stated their preference. Every attendee was able to contribute, there was laughter, talk of pets from childhood and when their families had been at home; this prompted shared accounts between spousal and child/parent dyads. If people liked neither cats nor dogs the staff tutor asked about any animal they did like. This led to an attendee with dementia hesitantly telling the group about the birds which they chased with sticks in the garden. They had difficulty with word-finding, but were given time to tell their account. As the group discussed this image and shared laughter, we observed the person sitting a little taller in their chair and looking around the room more actively. The staff tutor started each week reminding people of the previous week's animal discussion, scaffolding more talk around this non-threatening topic. These examples demonstrate dementia course activities creating spaces for people to feel included and inter-connected to others.

DISCUSSION AND IMPLICATIONS

Summary of findings and comparison with existing literature

The concept of recovery-focused care being appropriate for people with dementia was raised as early as 2010 by Hill. However, ours seems to be the first empirical evaluation to identify the specific contextual and constituent features of Recovery College dementia courses and what outcomes can be for people with dementia in either peer-tutor or attendee roles. Drawing on data collected during a realist evaluation we consider underlying causal processes, or mechanisms, triggered by varying contextual features of five recovery-focused dementia courses. We do not discuss what works in a mechanistic or evaluative sense as our findings indicate that what works depends on who the person is and context. The mechanisms evident within our CMOCs (supplementary file 3) and these 'stand-out' exemplars can be seen to illustrate theories which align with the CHIME framework, namely: Connectedness, Hope through positive reframing, non-stigmatized Identity and Empowerment. We now discuss these in relation to dementia literature and post-diagnostic support principles.

Connectedness Attending a Recovery College course can enable people with dementia to maintain a social self. By connecting and taking time to inter-relate with others with similar experiences, loneliness in people with dementia can be counteracted. Structuring the course with time for informal talk between attendees and tutors, connects people through shared interests or humour, not just through the dementia label. The importance of enabling different relationships beyond 'person with lived experience' and 'family supporter' has been highlighted in general Recovery College course evaluations (Toney et al., 2018; Reid et al., 2020) and in dementia literature (Birt et al., 2020). Additionally, as co-produced psychoeducation is a collaborative and interactive process that creates value through meaningful exchanges, attendees with dementia can connect

despite differing levels of engagement, by interacting verbally or non-verbally, watching and listening. Providing a variety of materials and media with which attendees can connect with may be important for the inclusion of people who have limited literacy or verbal skills. Tutors also need to attend and respond to non-verbal and tentative verbal approaches in order to connect with the person with dementia and bring them into the conversation (Braithwaite et al 2022).

Hope through positive reframing Meeting other people with dementia can help individuals reframe their experiences and foster hope. Generating and maintaining hope is an interpersonal process (Dufault & Martocchio, 1985; Miller, 1985) and after a dementia diagnosis, people may face challenges in adjusting expectations (Wolverson et al., 2010). Comparing their situation with others and learning coping strategies from peers can foster hope (Amponsem et al. 2023). Social interactions create opportunities for experiencing fun and to affirm people's continuing capacity for positive experiences. Such reciprocity and reaffirming support help generate more hopeful experiences (Jackman et al., 2024). However, dementia is a syndrome of signs and symptoms with lived experiences shaped by individual psychosocial influences including co-morbidities, personal and social resilience, alongside culture and beliefs. In each course in our study, tutors acknowledged complex debilitating symptoms, and carer strain. To uncritically imply that a recovery-focused approach to post-diagnostic support enables people to 'live well' across the whole trajectory of the illness risks creating personal and societal narratives that one has failed if contextual factors such as cognitive ability, co-morbidity, relationships and socio-economic circumstances restrict a person's ability to be connected, to have choice and control. Rather than theorizing recovery in dementia as another feature of successful ageing it is more appropriate to position recovery as an '*ongoing process of accommodation and moving beyond what has happened*' (Perkins et al., 2016:5). To suggest that a person with dementia can recover a life only if they stay socially connected, continually live meaningful lives and have control over their life is reductionist. This narrative may lead to a person or family supporter masking physical and cognitive decline and any increasing distress. Such masking, or lack of attention to decline, risks reducing societal empathy and limited access to support.

Non-stigmatized identity Our findings highlight the importance of creating and exemplifying non-judgmental spaces, non-stigmatizing spaces, where the contributions of people with dementia are of equal value to those of healthcare staff and family supporters. By sharing and building peer experiences, people with dementia are encouraged to recover a non-stigmatized life after diagnosis (Mukadam & Livingston, 2012). Peer-tutors with dementia bring authenticity to their interactions with attendees, where they can connect through sharing experiences in an immediate, validating, and empathetic way. However, attendees' experiences will be diverse and intragroup interactions needs exploring further. In our study, people were predominantly sign posted to in-person courses but in online courses tutors had to react to unknown attendees. Peer-tutors with dementia were supported to accomplish complex occupational and social activities and they could see the benefits attendees gained, thus potentially increasing peer tutor sense of self-worth and confidence. These

findings align with other evidence that people with dementia can and do maintain social connections and are involved in helping others, so sustain a non-stigmatized identity (Birt et al., 2020); affirming self-hood (Hennelly et al., 2021). A Recovery College dementia course is not only a social setting but also one which offers learning about dementia and experiences of how people can navigate life positively with dementia, so replacing guilt and shame with validation and empowerment. However, Reid and colleagues' (2020) evaluation of a recovery education centre noted that deconstructing self-stigma was an ongoing practice. This highlighted for us that while peer-tutors in our study did demonstrate and articulated self-esteem and purposeful activity, this could not reliably evidence longer-term positive outcomes for attendees. Our CMOC (Theme One) indicated an outcome for people with dementia attending Recovery Colleges was to develop or maintain a stigma-free identity. Further evidence is needed on the longer-term impact of single courses and if longer-term sustainable post-diagnostics recovery focused support is needed (Moniz-Cook & Mountain, 2023).

Empowerment through safe uncertainty People often attend Recovery College dementia courses quite soon after diagnosis. This can be a time when people feel emotionally unsafe as they face a health threat, and individuals and family supporters experience concerns about each other's wellbeing (Moniz-Cook et al., 2006). The learning embedded in Recovery College courses may be essential to help people with dementia gain a sense of emotional safety (Kuske et al., 2021). Recovery-focused and person-centered post-diagnostic support gives control to the person with dementia. The ethos of encouraging people to be empowered and have choice even if these are deemed risky by others (Clarke et al., 2011), may be seen to reflect the theory of 'safe uncertainty' articulated by Mason, 2022. When under stress, people often wish for certainty and that clear decisions are made for them, but that this in itself may bring negative outcomes (Mason et al., 2022). A more therapeutic framing of options is to accept there are no definitive solutions or ways to sort the 'problem' (here a dementia-diagnosis). Instead, there needs to be a shared process of learning to manage the uncertainty that life brings and to use personal resources to deal with everyday life (Mason, et al., 2022). Such active learning aligns with framing recovery as an ongoing and personal process (Leamy et al., 2011) as Recovery Colleges may empower people with skills to consider ways to manage future challenges (Hill et al., 2010). Having choice, control and self-determination are all associated with empowerment in people with dementia (van Corven et al., 2021). Mental health experience-based co-production initiatives are designed, and shown to support people to make sense of real-life problems and find ways to move forward by learning from the past to shape the future, even when they are uncertain (Palmer et al., 2019).

Study Limitations

We acknowledge the limitation of recruiting from just four sites where our case study ethnographic approach allowed in-depth observations of diverse course-delivery styles. Recovery College dementia courses are relatively new and require future research to evaluate the longer-term impact of this form of post-diagnostic

support, and the impacts for different people. Specifically, there is more work needed to understand if the use of the term Recovery is appropriate in the context of post-diagnostic support. We sought, but did not achieve, an ethnically diverse sample despite recruiting from Recovery Colleges in areas with ethnically diverse communities. Known barriers to attending mental health services for both diagnosis and support might explain limited recruitment of non-white British people in this small sample. Another limitation could be the absence of detail demographics on the sample. We deliberately chose not to record demographic information on those in the observations as we considered this could further highlight the presence of researcher. However, collecting demographic data on the those interviewed would have provided greater granular data on the micro contextual factors of participants. There is a need to consider cultural tailoring for international use with studies undertaken with other groups.

Conclusion and recommendations

This study is the first to examine co-production, co-facilitated peer support within the context of Recovery College dementia courses - a distinct and novel form of recovery-focused post-diagnostic dementia support. In-depth case study methodology has offered themes associated with positive constructs such as connectedness, hope, empowerment and counteracting a stigmatised identity associated with a dementia-diagnosis. This study reflects a next step in identifying how recovery-focused post-diagnostic support might enable people to have hope for the future following a dementia-diagnosis. Nonetheless there is scope for more detailed exploration of recovery-focused, post-diagnostic dementia support which should consider the ways in which intra group interaction occurs and the role of peer support between attendees as well as between peer-tutor and attendees. Trial research could provide an evidence base on efficiency of this form of post diagnostic dementia support providing empirical evidence as to whether wider implementation is justified. To understand cultural mechanisms there is scope to compare UK with international Recovery College models. We suggest the context mechanism and outcomes outlined in this paper set parameters for future research to design conceptually-driven post-diagnostic psychosocial intervention studies in dementia.

Funding and conflict of interest We have no conflicts of interest to disclose.

This study is funded by the National Institute for Health and Social Care Research (NIHR), NIHR Health and Social Care Delivery Research NIHR131676, 2022-2024]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

This project is affiliated with the Inclusive Involvement in Research for Practice-led Health and Social Care within

the NIHR East of England, which has supported Poland and Birt's time on this study. It develops work undertaken by West in her Collaboration for Leadership in Applied Health Research & Care (CLAHRC) East of England Research Fellowship (2019).

Chris Fox is part-funded by the National Institute for Health and Care Research (NIHR) HealthTech Research Centre in Dementia.

Acknowledgements The authors thank all those who took part in the study enabling us to observe sessions and speak with tutors and attendees across England. Thank you to the study manager Thomas Rhodes for expert guidance on protocol and ethical management. This study was actively supported by two advisory groups; we thank the Partners in Research (Patient and Public Involvement and Engagement) group who, with the support and expertise of Rachael Litherland from Innovations in Dementia, actively contributed to our analytical processes, providing perspectives from people living with dementia, and from family supporters. Thank you to all the NHS memory and dementia service and Recovery College staff who formed our staff advisory group helping to ensure outcomes resonated with practice needs. Thanks also to the wider DiSCOVERY study team: Ruth Mills, Kathryn Sams, Leanne Hague, Claire Duddy, Charlotte Wheeler, Maria Sanchez and Robert Kelly. Correspondence concerning this article should be addressed to Linda Birt, University of Leicester, United Kingdom. Email: linda.birt@leicester.ac.uk

Data availability statement

The data that support the findings of this study are available on request from the corresponding author, [LB]. The data are not publicly available due to the sample sample full pseudonymized data sets may comprise the privacy of research participants.

References

- Amponsem, S., Wolverson, E., & Clarke, C., (2023). The meaning and experience of hope by people living with dementia as expressed through poetry. *Dementia*, **22**(1), 125–143. <https://doi.org/10.1177/14713012221137469>
- Bamford, C., Wheatley, A., Brunskill, G., et al. (2021). Key components of post-diagnostic support for people with dementia and their carers: A qualitative study. *PloS one*, **16**(12). <https://doi.org/10.1371/journal.pone.0260506>
- Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, **39**(2), 199–211. <https://doi.org/10.1111/1467-9566.12530>
- Birt, L., Griffiths, R., Charlesworth, G., et al. (2020). Maintaining Social Connections in Dementia: A Qualitative Synthesis. *Qualitative Health Research*, **30**(1), 23–42. <https://doi.org/10.1177/1049732319874782>
- Birt, L., West, J., Poland, F., et al. (2023). Protocol for a realist evaluation of Recovery College dementia courses: understanding coproduction through ethnography. *BMJ open*, **13**(12), e078248. <https://doi.org/10.1136/bmjopen-2023-078248>
- Birt, L., Fox, C., Alam, J., et al. (2025). Co-produced, peer supported post-diagnostic dementia support: a realist evaluation of Recovery College courses. Pre print [10.21203/rs.3.rs-7145910/v1](https://doi.org/10.21203/rs.3.rs-7145910/v1)
- Braithwaite Stuart, L., Hedd Jones, C. & Windle, G. (2022) A qualitative systematic review of the role of families in supporting communication in people with dementia. *International Journal of Language & Communication Disorders*, **57**, 1130–1153. <https://doi.org/10.1111/1460-6984.12738>
- Clarke, C. L., Wilcockson, J., Gibb, C. E., Keady, J., Wilkinson, H., & Luce, A. (2011). Reframing risk management in dementia care through collaborative learning. *Health & Social Care in the Community*, **19**(1), 23–32. <https://doi.org/10.1111/j.1365-2524.2010.00944.x>
- Department of Health. (2009). National Dementia Strategy Living well with dementia: A National Dementia Strategy Putting People First. https://assets.publishing.service.gov.uk/media/5a7a15a7ed915d6eaf153a36/dh_094051.pdf
- Dooley, J., Webb, J., James, R., Davis, H., & Read, S. (2025). Exploring experiences of dementia post-diagnosis support and ideas for improving practice: A co-produced study. *Dementia*, **0**(0). <https://doi.org/10.1177/14713012241312845>
- Downs, M., & Lord, K. (2017). Person-Centered Dementia Care in the Community: A Perspective from the

United Kingdom. *Journal of Gerontological Nursing*, **43**(08), 11-17. <https://doi.org/10.3928/00989134-20170515-01>

Dufault, K., & Martocchio, B. C. (1985). Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *The Nursing Clinics of North America*, **20**(2), 379–391.

Handley, M., Wheeler, C., Duddy, C., et al. (2024). Operationalising the Recovery College model with people living with dementia: a realist review. *Aging & Mental Health*, **28**(8), 1078–1089.
<https://doi.org/10.1080/13607863.2024.2356878><https://doi.org/10.1080/13607863.2024.2356878>

Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2021). Personhood and Dementia Care: A Qualitative Evidence Synthesis of the Perspectives of People With Dementia, *The Gerontologist*, **61**(3), e85–e100. <https://doi.org/10.1093/geront/gnz159>

Hill, L., Roberts, G., Wildgoose, J., Perkins, R., & Hahn, S. (2010). Recovery and person-centred care in dementia: common purpose, common practice? *Advances in Psychiatric Treatment*, **16**(4), 288–298.
<https://doi.org/10.1192/apt.bp.108.005504>

Jackman, V., Wolverson, E., Clarke, C., & Quinn, C. (2024). A participatory approach to understand what might be most meaningful to people living with dementia in a positive psychology intervention. *Aging & Mental Health*, **28**(8), 1090–1099. <https://doi.org/10.1080/13607863.2023.2299967>

Jethwa, J., Hunter-Brown, H., & Senkoy, A. *Memory Services National Accreditation Programme (MSNAP) Standards: Standards for Memory Services*. London; 2024.
[https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---9th-edition-\(2024\).pdf?sfvrsn=8c42ae6c_3](https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---9th-edition-(2024).pdf?sfvrsn=8c42ae6c_3)

Jones-Hooker, C., & Tyndall, D. E. (2023). Application of case study research and ethnography methods: Lessons learned. *Applied Nursing Research*, **73**, 151713. <https://doi.org/10.1016/j.apnr.2023.151713>

Jopling, K. (2017). *AGE UK report: promising approaches to living well with dementia*.
https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb_feb2018_promising_approaches_to_living_well_with_dementia_report.pdf

Kenny, J., Asquith, I., Guss, R., et al. (2016). Facilitating an evolving service user involvement group for people with dementia: What can we learn? *The Journal of Mental Health Training, Education and Practice*, **11**(2), 81–90. <https://doi.org/10.1108/JMHTEP-09-2015-0046>

Kuske, S., Borgmann, S. O., Wolf, F., & Bleck, C. (2021). Emotional Safety in the Context of Dementia: A Multiperspective Qualitative Study. *Journal of Alzheimer's disease*, **79**(1), 355–375.

<https://doi.org/10.3233/JAD-201110>

Leamy, M., Bird, V., Boutillier, C.L., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *British Journal of Psychiatry*, **199**(06), 445–452. <https://doi.org/10.1192/bjp.bp.110.083733>

Lowen, C., Birt, L., & West, J. (2019). Recovery Colleges and dementia courses – a scoping survey, *Mental Health and Social Inclusion*, **23**(4), 166-172. <https://doi.org/10.1108/MHSI-08-2019-0024>

Low, L.F., Swaffer, K., McGrath, M., & Brodaty, H. (2018). Do people with early stage dementia experience Prescribed Disengagement®? A systematic review of qualitative studies. *International Psychogeriatrics*, **30**(6), 807–831. <https://doi.org/10.1017/s1041610217001545><https://doi.org/10.1017/s1041610217001545>

Manzano, A. (2016). The craft of interviewing in realist evaluation. *Evaluation*, **22**(3), 342-360. <https://doi.org/10.1177/1356389016638615>

Mason, B. (2022). Towards positions of safe uncertainty. *Human Systems*, **2**(2), 54-63. <https://doi.org/10.1177/26344041211063125>

Miller, J.F. (1985). Inspiring Hope. *The American Journal of Nursing*, **85**(1), 22. <https://doi.org/10.2307/3463675>

Moniz-Cook, E., & Mountain, G. (2023). The memory clinic and psychosocial intervention: Translating past promise into current practices. *Frontiers in Rehabilitation Sciences*, **4**, 1052244. <https://doi.org/10.3389/fresc.2023.1052244>

Moniz-Cook, E., Manthorpe, J., Carr, I., Gibson, G., & Vernooij-Dassen, M. (2006). Facing the future: A qualitative study of older people referred to a memory clinic prior to assessment and diagnosis. *Dementia*, **5**(3), 375–395. <https://doi.org/10.1177/1471301206067113>

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: approaches and goals. *Aging Health*, **8**(4), 377–386. <https://doi.org/10.2217/ahe.12.42>

NHS England (2024). *Dementia programme and preparation for new Alzheimer’s disease modifying treatments*. <https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/><https://www.england.nhs.uk/long-read/dementia-programme-and-preparation-for-new-alzheimers-disease-modifying-treatments/>

Oh, H. (2013). The pedagogy of recovery colleges: clarifying theory. *Mental Health Review Journal*, **18**(4). <https://doi.org/10.1108/MHRJ-07-2013-0026>

Palmer, V. J., Weavell, W., Callander, R., et al. (2019). The Participatory Zeitgeist: an explanatory theoretical

- model of change in an era of coproduction and codesign in healthcare improvement. *Medical Humanities*, **45**(3), 247–257. <https://doi.org/10.1136/medhum-2017-011398>
- Pawson, R., & Tilley, N. (1997). *Realistic evaluation*. Sage.
- Perkins, R., Repper, J., Rinaldi, M., & Brown, H. (2012). *Implementing Recovery through Organisational Change: Briefing paper*. Centre for Mental Health. <https://static1.squarespace.com/static/65e873c27971d37984653be0/t/668cedec6ea5392f6ac0ef31/1720511981544/1.Recovery-Colleges.pdf>
- Perkins, R., Hill, L., Daley, S., Chappell, M. and Rennison, J. (2016), “Continuing to be me – recovering a life with a diagnosis of dementia”, Briefing Paper launched at ImROC on 30 September. Available at <https://www.slamrecoverycollege.co.uk/uploads/2/6/5/2/26525995/continuing-to-be-me-recovery-and-dementia-briefing-sept-2016.pdf>.
- QSR International Ltd. NVivo (released in March 2020). <https://www.qsrinternational.com/nvivo-qualitative-data-analysissoftware/home>
- Reid, N., Khan, B., Soklaridis, S. et al. (2020). Mechanisms of change and participant outcomes in a Recovery Education Centre for individuals transitioning from homelessness: a qualitative evaluation. *BMC Public Health*, **20**, 497. <https://doi.org/10.1186/s12889-020-08614-8>
- Toney, R., Elton, D., Munday, E., et al. (2018). Mechanisms of Action and Outcomes for Students in Recovery Colleges. *Psychiatric services* (Washington, D.C.), **69**(12), 1222–1229. <https://doi.org/10.1176/appi.ps.201800283>
- van Corven, C. T. M., Bielderma, A., Wijnen, M., et al. (2021). Empowerment for people living with dementia: An integrative literature review. *International Journal of Nursing Studies*, **124**, 104098. <https://doi.org/10.1016/j.ijnurstu.2021.104098>
- Wall, S. S. (2015). Focused Ethnography: A Methodological Adaptation for Social Research in Emerging Contexts. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, **16**(1). <https://doi.org/10.17169/fqs-16.1.2182>
- Walsh, S., Merrick, R., Milne, R., Nurock, S., Richard, E., & Brayne, C. (2024). Considering challenges for the new Alzheimer’s drugs: Clinical, population, and health system perspectives. *Alzheimer’s & Dementia*, **20**(9), 6639–6646. <https://doi.org/10.1002/alz.14108>
- Watts, S., Cheston, R., Moniz-Cook, E., Burley, C., & Guss, R. (2014). Post-diagnostic support for people living with dementia. In R. Guss et al. *Clinical psychology in the early-stage dementia care pathway*. Leicester: British Psychological Society.

West, J., Birt, L., Wilson, D., Mathie, E., & Poland, F. (2022). A case study of co-production within a mental health Recovery College dementia course: Perspectives of a person with dementia, their family supporter and mental health staff. *Frontiers in Rehabilitation Sciences*, **3**, 920496.

<https://doi.org/10.3389/fresc.2022.920496>

Windle, G., Roberts, J., MacLeod, C., et al. (2023). 'I have never bounced back': resilience and living with dementia. *Aging & Mental Health*, **27**(12), 2355–2367. <https://doi.org/10.1080/13607863.2023.2196248>

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040. In *CPEC Working Paper 5*. <https://www.infocoponline.es/pdf/Working-paper-5-Wittenberg-et-al-dementia.pdf>

Wolverson, E.L., Clarke, C. and Moniz-Cook, E. (2010). Remaining hopeful in early-stage dementia: a qualitative study. *Aging & Mental Health*, **14**(4), 450–460. doi: 10.1080/13607860903483110

Wolverson, E., Hague, L., West, J., et al. (2024), Building an initial understanding of UK Recovery College dementia courses: a national survey of Recovery College and memory services staff, *Working with Older People*, **28**(2), 108–119. <https://doi.org/10.1108/WWOP-02-2023-0003>

Table 1 Sample Characteristics

	<i>Case study A</i>	<i>Case study B</i>	<i>Case study C</i>	<i>Case study D</i>	
<i>Method of delivery</i>	In person 2.5 hours 3 sessions over 3 weeks	Online 1 hour 3 sessions over 3 weeks	In person 2.5 hours single session	Online 2 hours Single session	In person 2 hours single session
<i>Delivery team</i>	2 staff tutors 1 peer-tutor with dementia 2 peer-tutor family supporters	2 staff tutors 1 peer-tutor family supporter	1 staff tutor 1 peer-tutor with dementia 1 peer-tutor family supporter	1 staff tutor 1 peer-tutor with dementia	1 staff tutor 1 peer-tutor with dementia
<i>Attendees</i>	N=9 4 spousal dyads (4 people with dementia) 1 service manager	N=11 2 people with dementia 8 family carers 1 staff member	N=13 4 people with dementia 5 family/friend supporters 1 volunteer 3 support staff	N= 20 4 people with dementia 7 family supporters 8 staff 1 support staff	N= 33 5 people with dementia 9 family supporter 18 staff members 1 support staff
<i>Interviews</i>	N=10 2 staff tutors 1 peer-tutor with dementia 2 peer-tutor family supporters 2 attendees with dementia 2 attendee family supporters 1 attendee service manager	N=7 2 staff tutors 1 peer-tutor family supporter 3 attendee family supporters 1 attendee service manager	N=10 1 staff tutor 1 peer-tutor with dementia 1 peer-tutor family supporter 2 attendees with dementia 2 attendee family supporters 1 attendee volunteer 1 support staff 1 service manager	N=5 1 staff tutor 1 peer-tutor with dementia 2 attendee family supporters 1 attendee staff member	N=12 4 attendees with dementia 6 attendee family supporters 2 attendee staff member

Figure 1 Theme 1 Empowering and enabling non-stigmatized identities

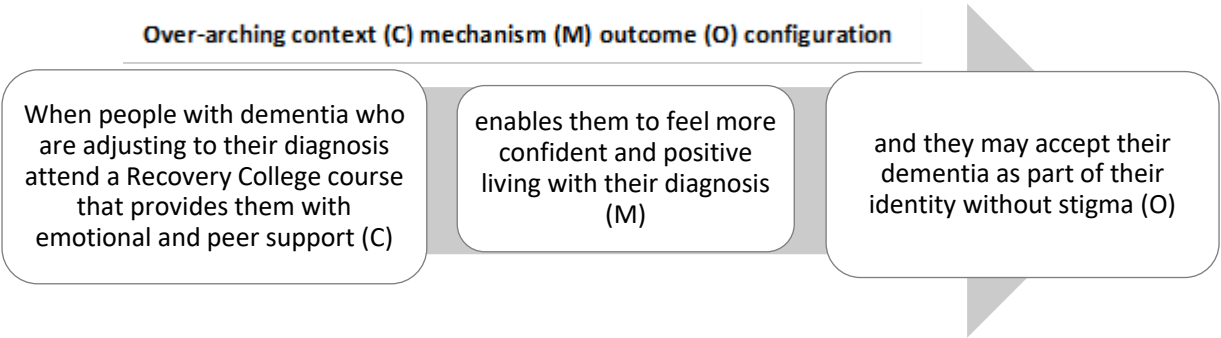


Figure 2 Theme 2 Managing uncertainty for positive reframing

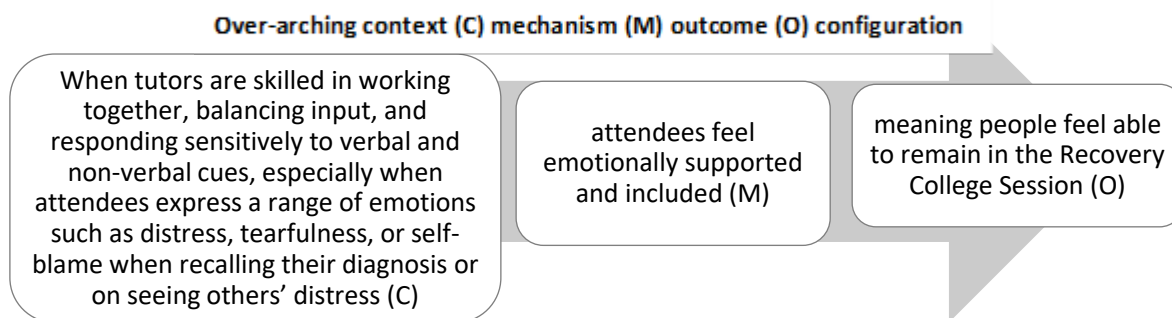
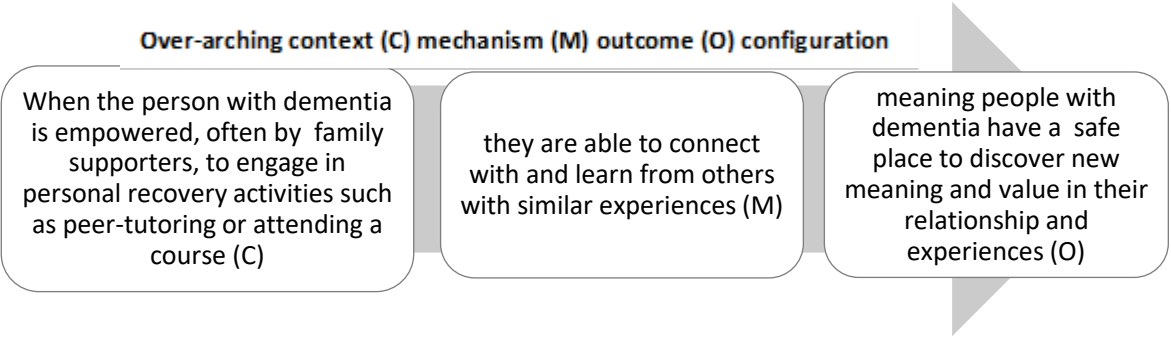


Figure 3 Theme 3 Connecting together enabling hope



Supplementary File 1: Recovery Colleges

The first UK Recovery College was set up in 2009, growing to 85 by 2017 (Perkins, Meddings, Williams & Repper, 2018). The model has been replicated internationally with Recovery Colleges now in existence or developing in 22 countries (King & Meddings, 2019). The recovery model is flourishing in adult statutory mental health services, encouraged since 2011 by the Department of Health commissioned 'Implementing Recovery through Organisational Change' (ImROC) collaborative <https://imroc.org/>. A recovery-focused, peer-led psychoeducation approach is adopted and embedded within strategic care delivery in mental health Trusts, to complement clinical care and improve outcomes beyond a narrow focus on symptom reduction, to help people rebuild meaningful, satisfying lives, despite limitations caused by mental health difficulties (Perkins et al., 2018).

Recovery Colleges operate using five key linked conceptual processes - the CHIME recovery framework – robustly developed to underpin the term recovery in this context: **Connecting** with others, inspiring **Hope**, maintaining a positive **Identity**, finding **Meaning** and purpose in life outside of symptoms and **Empowering** control over life and a focus on strengths (Leamy, Bird, Boutillier, Williams & Slade, 2011). Recovery College courses offer access to distinctive peer support both from co-producing courses and/or attending them (Sommer, Gill & Stein-Parbury, 2018). Recovery Colleges create adult learning environments which moderate power dynamics between service users and staff, to reduce stigma and increase attendees' sense of hope and empowerment (Meddings, Byrne, Barnicoat, Campbell & Locks, 2014; Sommer et al., 2018; Zabel, Donegan, Lawrence & French, 2016). Attendees report developing novel coping strategies, improving self-worth, wellbeing and quality of life (Meddings et al., 2014; Rinaldi, Marland & Wybourn, 2012; Wilson, King & Russell, 2019; Zucchelli & Skinner, 2013). Implementing a recovery-focused approach through Recovery Colleges has been widely evidenced as bringing benefits as well as challenges to access (Allard et al., 2024; Bowness et al., 2023; Whitley et al., 2019).

A typical adult mental health Recovery College offers courses on mental health and recovery, designed to increase attendees' knowledge, skills and confidence in self-management of their own mental health and wellbeing. Courses range from one-off sessions to several sessions spread over a set number of weeks. All courses are co-produced and co-delivered by peer tutors - that is, people with lived/expert experience - and mental health staff. Peer tutors prepare for their role through having training to teach and support, and receive supervision to ensure any sensitive issues can be supported effectively. A theory of change model for Recovery Colleges has been co-developed within adult mental health contexts that identifies four mechanisms of change (Toney et al., 2018) empowering environment - opportunities for choices; shifting balance of power; enabling different relationships and connecting with peers; and facilitating personal growth through shared learning and strength-building. Outcomes include changes in the attendee including improved wellbeing, reinforced by life changes they could observe. This model is highly applicable to enabling desired outcomes for post-diagnostic support in dementia.

The CHIME Recovery framework (Leamy et al., 2011) as operationalised through Recovery Colleges, has clear links with the NICE-recommended person-centred care framework for dementia (Brooker & Latham, 2016), the Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP; Jethwa, Fern, Abhayaratne & Wariabharaj, 2022) and the National Dementia Strategy objective to develop peer support and learning networks (Department of Health, 2009). Key domains for person-centred care are **valuing** people living with dementia and those (both informal family and friends and health and social care staff) who care for them; providing care that is **individualised**; understanding and acting from the **perspectives** of people living with dementia - which can reinforce connections, meanings and identities; and creating positive **social-psychological** environments - which can build hope and empowerment (Brooker & Latham, 2016).

Five recovery processes giving the acronym CHIME

Connectedness with others; inspiring Hope and optimism about the future; maintaining a positive Identity; finding Meaning in life outside of symptoms; and Empowerment with control over life and a focus on strengths.	(Leamy et al., 2011)
---	-------------------------

References

- Allard, J., Pollard, A., Laugharne, R., et al. (2024). Evaluating the impact of a UK Recovery College on mental well-being: pre- and post-intervention study. *BJPsych open*, 10(3), e87.
<https://doi.org/10.1192/bjo.2023.646>
- Bowness, B., Hayes, D., Stepanian, K., et al. (2023). Who uses Recovery Colleges? Casemix analysis of sociodemographic and clinical characteristics and representativeness of recovery college students. *Psychiatric rehabilitation journal*, 46(3), 211–215. <https://doi.org/10.1037/prj0000532>
- Brooker, D., & Latham, I. (2016). *Person-centred dementia care making services better with the VIPS framework (2nd ed.)*. London Philadelphia: Jessica Kingsley Publishers.
- Department of health. (2009). *National Dementia Strategy Living well with dementia: A National Dementia Strategy Putting People First*. https://assets.publishing.service.gov.uk/media/5a7a15a7ed915d6eaf153a36/dh_094051.pdf
- Jethwa, J., Fern, M., Abhayaratne, C., & Wariabharaj, K. (2022). *Quality Standards for Memory Services Eighth Edition*. [https://www.rcpsych.ac.uk/docs/default-source/improving-are/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-\(2022\).pdf?sfvrsn=d8341549_2](https://www.rcpsych.ac.uk/docs/default-source/improving-are/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2)
- King, T., & Meddings, S. (2019). Survey identifying commonality across international Recovery Colleges. *Mental Health and Social Inclusion*, <https://doi.org/10.1108/mhsi-02-2019-0008>
- Leamy, M., Bird, V., Boutillier, C. L., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *British Journal of Psychiatry*, 199(06), 445–452.
<https://doi.org/10.1192/bjp.bp.110.083733>
- Meddings, S., Byrne, D., Barnicoat, S., Campbell, E., & Locks, L. (2014). Co-delivered and co-produced: creating a recovery college in partnership. *The Journal of Mental Health Training, Education and Practice*, 9(1), 16–25.
<https://doi.org/10.1108/jmhtep-04-2013-0011>
- Perkins, R., Repper, J., Rinaldi, M. and Brown, H.(2012), *Recovery Colleges, Implementing Recovery Through Organisational Change*, London.
- Perkins, R., Hill, L., Daley, S., Chappell, M., & Rennison, J. (2016). 12. 'Continuing to be me'—Recovering a life with a Diagnosis of Dementia. Available from
<https://www.slamrecoverycollege.co.uk/uploads/2/6/5/2/26525995/continuing-to-be-me-recovery-and-dementia-briefing-sept-2016.pdf>. Accessed on 1.08.2025
- Perkins, R., Meddings, S., Williams, S., & Repper, J. (2018). *Recovery Colleges 10 Years On. ImROC*.
<https://static1.squarespace.com/static/65e873c27971d37984653be0/t/668c0c17506df25c98d01377/1720454168113/ImROC-Recovery-Colleges-10-Years-On.pdf>
- Rinaldi, M., Marland, M., & Wybourn, S. (2012). *Annual Report 2011 – 2012 South West London Recovery College*. http://rfact.org.au/wp-content/uploads/2015/05/SW-London-Recovery-College-evaluation-2011_12-v1-0.pdf
- Sommer, J., Gill, K., & Stein-Parbury, J. (2018). Walking side-by-side: Recovery Colleges revolutionising mental health care. *Mental Health and Social Inclusion*, 22(1), 18–26.
<https://doi.org/10.1108/mhsi-11-2017-0050>
- Toney, R., Elton, D., Munday, E., Hamill, K., Crowther, A., Meddings, S., Taylor, A., Henderson, C., Jennings, H., Waring, J., Pollock, K., Bates, P., & Slade, M. (2018). Mechanisms of Action and Outcomes for Students in Recovery Colleges. *Psychiatric Services*, 69(12), 1222–1229.
<https://doi.org/10.1176/appi.ps.201800283>

- Wilson, C., King, M., & Russell, J. (2019). A mixed-methods evaluation of a Recovery College in South East Essex for people with mental health difficulties. *Health & social care in the community*, 27(5), 1353–1362. <https://doi.org/10.1111/hsc.12774>
- Whitley, R., Shepherd, G., & Slade, M. (2019). Recovery Colleges as a mental health innovation. *World Psychiatry*, 18(2), 141–142. <https://doi.org/10.1002/wps.20620>
- Zabel, E., Donegan, G., Lawrence, K., & French, P. (2016). Exploring the impact of the recovery academy: a qualitative study of Recovery College experiences. *The Journal of Mental Health Training, Education and Practice*, 11(3), 162–171. <https://doi.org/10.1108/jmhtep-12-2015-0052>
- Zucchelli, F.A., & Skinner, S. (2013). Central and North West London NHS Foundation Trust's (CNWL) Recovery College: the story so far *Mental Health and Social Inclusion*, 17(4), 183–189. <https://doi.org/10.1108/mhsi-07-2013-0023>

Supplementary File 2: Interview Topic Guides

Topic guide 1 – peer tutors – people with dementia and family supporters

Can you tell me about your experiences of co-producing and facilitating a Recovery College dementia course?

How did you become involved? Why did you become involved?

- *approached by a member of staff*
- *through the central Recovery College*
- *word of mouth or advert*

What have been the benefits of being involved?

What have been the challenges of being involved?

Can you tell me more about your role in co-developing the course?

- *who were you working with?*
- *how often did you meet and where?*

Was there already an idea for the course and how much do you think you helped to develop the course?

Were you happy with the level of involvement you had with developing the course?

Can you expand on that?

What support was provided for you as a coproduction partner?

- *financial*
- *practical (with technology/travel/accessing venues)*
- *emotional*

Who provided this support?

Did you experience any challenges for co-developing the course?

- *practical*
- *emotional*
- *time commitments*

How was your experience of working with the staff to co-produce the course?

- *supportive*
- *different from usual encounters with staff*
- *differences in power relations*

What do you see you gained from being involved with developing the course?

- *e.g. sense of purpose, new skills, confidence in skills, contributing by sharing own experience with others*

From your experience, do you think there are certain skills or motives that have helped you to co-produce the course?

- *confident with sharing experience*
- *willing to contribute*
- *ready to share experiences – can you expand on this?*

Can you tell me about your experience of running the course?

What support do you think you needed to run the course?

- *what worked well*
- *what did not work so well*

What do you think you have gained from running the course?

- *increase confidence*
- *chance to give back*

What do you think people gain from you running the course?

- *ideas that might help people live positively*
- *learning from and sharing experiences with others*
- *seeing someone with dementia leading the course and changing attitudes towards dementia*
- *increased knowledge of resources outside of the course (this could include links with other people)*

Are there negatives for you in running the course?

- *time-consuming*
- *difficult to talk about experiences?*
- *tiring*
- *level of expected involvement may not be in line with actual involvement*

Where and how is the course run?

- *online*
- *face-to-face*
- *what kind of venue?*
- *how often?*
- *for how long?*

Which do you prefer?

- *how do you think this impacts your experience of running the course?*
- *Why*

Which groups of people have you noticed come to the course?

- *people with dementia/supporters/staff?*
- *particular age group?*
- *background/ethnicity?*

Are there particular people/groups that you think aren't attending? Who? Why do you think this is?

- *transport/unable to access online*
- *lack of confidence*
- *aren't aware of the Recovery College*
- *think 'recovery' isn't relevant for people with dementia*
- *do not relate to the people running or attending course so think it is not for them*

How could more people be encouraged to attend dementia courses?

- *changes to how course is advertised (e.g. language/more widely advertised)*
- *buddy system/support with travel/technology)*

Are you involved with evaluating the course?

- *how is the course evaluated? (standard feedback form/questionnaire, more open-ended feedback welcomed?)*
- *is this information used to make changes to future courses?*
- *does it influence whether the course is run again?*

Anything else you would like to add?

Topic guide 2 – staff tutors

Can you tell me about your experiences of coproducing and facilitating a Recovery College dementia course?

How did you become involved? Why did you become involved?

What have been the benefits of being involved?

What have been the challenges?

Setting up a course What factors impact the decision to set up a Recovery College dementia course?

- *resources*
- *backing of certain individuals*
- *attitudes towards recovery in relation to dementia*
- *culture within the Trust*

What is the relationship between memory services and the Recovery College?

- *how do they complement one another?*
- *do they have differing aims?*
- *do memory services signpost people to the Recovery College?*

Who is the course open to?

- *people who have accessed services, supporters?*
- *staff?*
- *general public?*

How is the course advertised?

- *social media?*
- *through the Recovery College?*
- *through services?*
- *word of mouth?*
- *any other*

Are there particular groups of people you are aiming to reach with the Recovery College courses and what methods do you use to reach them?

Does this work?

Coproduction How important is coproduction to the course?

- *why is it important?*

What have been your experiences of coproducing the dementia course?

What would co-production of the course ideally look like?

- *is it possible? Why, or why not?*
 - *resources co-producers can access*
 - *time*
 - *decision-making*
- What level of co-production do you consider good enough?

What have been the benefits for you in coproducing the course?

- *ability to work in line with values?*
- *help to re-engage with day-to-day job*
- *professional growth*
- *personally rewarding (how?)*
- *decreased stress/burnout?*

What are the challenges of coproduction?

- *embracing a different power dynamic/valuing each person's involvement? (For you? For the people you're coproducing with?)*
- *amount of time it takes*
- *any difficulties with working with people with dementia specifically? (If yes, what are they, how do you address and overcome these?)*

How do you find people to coproduce courses with?

- *people you've worked with clinically*
- *through the central Recovery College*
- *word of mouth*

Are there certain skills, characteristics, or experience that you look for in a coproduction partner?

- *confident with sharing their experience*
- *willingness to contribute*
- *emotionally 'robust' enough?*

Can you tell me about a time when you were struggling to work in a co-productive way and what you did to address this?

- *the fact that they might benefit from the process*

What support is provided for coproduction partners (people with dementia and supporters)?

- *financial?*
- *practical (with technology/travel/accessing venues)?*
- *psychological/emotional?*

Who provides this support?

Has coproducing the course impacted your day-to-day job?

- *If yes, how and how have you managed this? (Affected interactions with other people with dementia? More likely to apply recovery-focused principles?)*

Running a course Where/how is the course run?

- *online/face-to-face?*
- *what kind of venue?*

How do you think this impacts the delivery of the course?

- *are people with dementia less able to use technology to attend online?*
- *does the course being face-to-face encourage more discussion or building of relationships?*

What have been the positives of running the course?

- *For you as a member of staff (chance to gain holistic view of people with dementia, to see them recovering and thriving, increase personal wellbeing, changed attitudes towards recovery)*
- *For peer tutors (increase confidence, chance to give back)*
- *For attendees (empowerment and self-management, a safe space, learning from and sharing experiences with others, seeing peers leading and succeeding, reduced stigma and more positive sense of self, able to visualise living well, see self as more than diagnosis, ability to build relationships that last outside of the course)*

And the negatives? *(time-consuming alongside other responsibilities)*

Have you felt supported whilst running the course?

- *by the Trust (if applicable) at organisation lead level or manager level?*
- *by fellow coproducers?*
- *by other colleagues?*
- *with administrative staff?*

Who comes along to the courses?

- *people with dementia/supporters/healthcare staff?*
- *particular age group?*
- *background/culture/ethnicity?*

Are there particular people that you think aren't attending?

- *Why do you think this is?*
 - *transport/unable to access online*
 - *lack of confidence*
 - *aren't aware of the Recovery College*
 - *think 'recovery' isn't relevant for people with dementia*
 - *don't think the course is for them (why might that be?)*

How could more people be encouraged to attend dementia courses?

- *more accessible language*
- *more widely advertised*
- *buddy system/support with travel/technology*
- *ensuring adverts and materials 'speak' to the people trying to reach*

Evaluating a course Do you evaluate the course?

- *How? (feedback form/questionnaire, more open-ended feedback welcomed?)*
- *Is this information used to make changes to future courses?*
- *Does it influence whether the course is run again?*

Anything else you would like to add?

Topic guide 3 – attendees – people with dementia and family supporters

Can you tell me about your experiences of attending a Recovery College dementia course?

How did you hear about the course?

- *from a member of staff / care team*
- *word of mouth*
- *social media*

Why did you decide to attend?

- *wanted to meet others in a similar situation*
- *wanted to learn strategies to live positively with dementia*
- *wanted to find out what a Recovery College is*

Where and how was the course run?

- *online/face-to-face?*
- *what kind of venue?*

Did you have any worries or concerns before joining the course?

- *getting there / joining online*
- *didn't feel confident enough, worried about talking or meeting others,*
- *what you might be expected to do during the course*
- *how you might feel during or after the course*
- *not sure if recovery is relevant to someone with dementia*

Do you think things could have been done to make the course easier to access?

- *If yes, in what way?*

How could more people be encouraged to attend Recovery College dementia courses?

- *easier to understand language*
- *more widely advertised*
- *easier ways to sign up*
- *buddy system / support with travel / technology*

Would you prefer courses online or in person?

- *Why?*

What have been the positive outcomes from attending the course?

- *learning from and sharing experiences with others,*
- *seeing people with dementia running the course*
- *improving how I see myself and my situation*
- *knowing where I might get help or thinking about how I can better manage*

What have been the negative points from attending the course?

How do you think the course could have been improved?

- *ratio between people with dementia / family supporters and staff*
- *did everyone get the chance to speak if they wanted to?*
- *did you see it as a safe space?*

Anything else you would like to add?

Topic guide 4 – attendees – staff

Can you tell me about your experiences of attending a Recovery College dementia course?

How did you hear about the course?

- *from another member of staff*
- *word of mouth*
- *social media*
- *through central Recovery College*
- *previous attendance at Recovery College*

Why did you decide to attend?

- *thought learning would be helpful in day-to-day role*
- *wanted to learn more about recovery and dementia*
- *wanted a different way of working with people with dementia*
- *wanted to find out more about the Recovery College*

Were there any barriers to you attending?

- *taking time out of work*
- *permission from line manager*

Or how were you encouraged to attend and why?

- *recommended by colleagues*
- *part of CPD*
- *considering role of coproducer*

Where and how was the course run?

- *online*
- *face-to-face? What kind of venue?*

Did this work for you? Why or why not?

Do you think the course could have been more accessible?

- *If yes, in what way?*

How could more people be encouraged to attend Recovery College dementia courses?

- *more accessible language (less recovery-focused?)*
- *more widely advertised*
- *support with travel/technology*

What have you gained from attending the course?

- *learning from and sharing experiences with others*
- *seeing people with dementia leading, succeeding, and living positively*
- *reduced stigma and changed attitudes towards people with dementia*

Were your expectations for the course met?

- *what were they?*
- *how and why or why not?*

How do you think the course could have been improved?

- *ratio between lived and professional experience*
- *how the course was facilitated*
 - *did everyone get the chance to speak if they wanted to*
 - *did it feel like a safe space?*

What was your understanding of recovery in the context of dementia before attending? Did this change after attending the course?

- *not recognised as important by colleagues*

Was there any learning that you will take back to your day-to-day role?

Anything you would like to add?

Topic Guide 5 – Relating to Equality Diversity and Inclusion

This part of the xx study is about trying to understand what we need to consider in Recovery College dementia courses to best support people from ethnic and cultural minorities with understanding dementia. So this is a very open, exploratory interview – not seeking a particular angle or answer at all, just really interested in hearing your views.

In our prior conversation [*prep for interview*], you mentioned that people from ethnic and cultural minority groups are under-represented in both your memory services and the Recovery College course. So thinking about the whole process and pathway, why do you feel that may be the case? What do you feel is the ‘sticking point’?

[You can think about it from the angle of the service users themselves, or other healthcare professionals, or services, systems]

To what extent do you feel that people may feel excluded from services or are choosing not to engage?

Where do you feel that people seek or receive a diagnosis and post-diagnostic support if not from formal health services? Do you know of any other services which pick people up later in their journey?

What do you feel could be some of the unmet needs that ethnic minority people with dementia could have post-diagnosis due to current levels of support, if any?

What do you feel could be some of the wider drivers of under-representation in this group the Recovery College? i.e. geography, socioeconomic, health beliefs of dementia etc

Moving Ahead:

1. What do you feel we in Recovery Colleges and/or the wider health service could do better to attract ethnic and cultural minorities into courses?
2. What do you feel that Recovery Colleges could offer ethnic minority participants that is different or unique to other forms of support?
3. Does your Recovery College currently support or pay for the additional costs of running the courses i.e. travel costs, room, refreshments etc? How is this paid for? Is there anything else that you would like funding for to engage minorities in the course that may be helpful?

4. How do you feel that your current dementia Recovery College courses could or would need to change to better engage and support ethnic and cultural minority people?

Supplementary File 3: Details on context (C) mechanism (M) and outcome (O) configurations

(CMOCs) which underpin the programme theories relating to outcomes for people with dementia, and family supporters as partners in coproducing and attending Recovery College dementia courses

Theme 1 Empowering and enabling non-stigmatized identities: When people with dementia who are adjusting their diagnosis attend a Recovery College course that provides them with emotional and peer support (C) enables them to feel more confident and positive living with their diagnosis (M) and they may accept their dementia as part of their identity without stigma (O))

Context-Mechanism-Outcome-Configuration (CMO)	Data example/s
EVAL CMOC1 If people learn about the types of dementia (C) then they understand it is beyond their control and they are not to blame (M) because they are able to reduce self-stigma as dementia is assimilated and maintained in their identity (O)	CS1-01 attendee with dementia: I felt a lot better when I came out. I went with a guilty conscience and I was frightened to think what I'd done wrong to deserve this, because I don't like the way I am. I thought, "Nobody will like me because of what I've got." I met one or two and I didn't talk to many people because I was scared, but when I came to you, I heard them people talking the way they felt. I thought, "If they've got it, not everybody could be wicked," and I thought, "No, I don't feel wicked no more." I know I've got this disease, but I'm still trying to find out how I got it and what's happening. CS2.2-21 attendee with dementia: I mean, it's lovely, I think, for all of us to see her up there and talking to us, and everything. Interviewer: So why is that? Why is that important? CS2.2-21: Well, because I think once you've been diagnosed, you tend to go into your own little world, and some things that I do, I think, "Is that me or is it the dementia?" And, honestly, you don't know sometimes. ... I think it's difficult for you people, because there are so many of us that have dementia, but we don't know what type or what the other person is going to ... And I can't think of any other way out of it, really. I mean, we've been married 62 years coming up, and it's ... I don't know. It seems to have shattered everything, and I don't know how to rectify it because it's me that's causing it.
EVAL CMOC2 If the course provides knowledge about living positively alongside symptoms of dementia (C) it can motivate and empower a sense of agency and control over their futures for attendees with dementia (M) because peer tutors inspire attendees through sharing their personal recovery journey of living alongside their dementia symptoms (O)	Interviewer: So that's a really important thing that you're the same as other people. CS3-03 attendee with dementia: That's right yes. There's a lot of people unfortunately lose their memory. I still cook every day and you know, so I'm not that bad but I am a bit forgetful at times. Interviewer: It's important to keep doing things. CS3-03: And I'm determined to keep cooking every day and I occasionally make a few buns and things. I don't do quite so much as I used to. CS1-06 attendee family supporter: it's hard to explain with my mum. It's not that she can't take on board that she's got dementia. I think she's just dismissive of it or doesn't really – you know, but yes, I think now that she's openly said it, I think that we can talk about it and be prepared and try and do all the things we can to help her really. CS2.2-30 attendee with dementia: Well, I've learnt a lot from what she was saying about her experiences and the fact that you look around and you see other people that you know that are in the same state. But, yeah, it educated me a bit more about it all, you know what I mean?
EVAL CMOC3 If people with dementia attend dementia courses following their diagnosis and courses are open for people to decide to attend when the	Interviewer: Do you think this is the right time for you two to come along to this type of session? CS2.2-28 attendee with dementia: Yeah. Interviewer: Very soon after you've been given that news. CS2.2-28: Yeah.

time feels right for them (C) then facilitators can create space for people to tell their story to be validated for the stage they are at (M) because attendees have an opportunity to process their diagnosis with the support of their peers (O)	Interviewer: Why is that? CS2.2-28: Well, just to know there's people out there with it and I am getting the help. CS1-02 attendee family supporter: For me, I mean I'm a very logical, very practical person, but sometimes if it all comes at once, you just go, "Hang on a minute, hang on a minute, I've had seven months of nobody being the slightest bit interested." All of a sudden, it all hits you at once. You think, "Hang on, calm down a bit." You need your mind to settle. Sometimes, you need your mind to settle. To settle on the diagnosis, understand what that means and then maybe a month, six weeks afterwards, attend the course when you've got your own head settled down. So I think that's a possibility.
EVAL CMOC4 If the course supports learning about the process of personal recovery together with peers (C) then it increases hope for a more positive message about living with dementia (O) because stigma is broken down in the room (M)	CS1-09 attendee with dementia: You could write on and say how you felt and what you think were causing it and I enjoyed it. Interviewer: What did you enjoy about doing that? CS1-09: Because I could let myself free. I did feel free. I know I'll never get rid of this. I know it. Interviewer: There was a word used in that group wasn't there called 'recovery'. CS1-09: Yes, but you can't – Interviewer: You can't recover from the disease – CS1-09: You can't recover from the disease, but they're right in one way. How can I put it? You can recover in yourself. The things you've thought are not true. So you know in your mind it's not you.
EVAL CMOC5 If attendees can learn the importance of maintaining connections with important people and activities in their lives (C) then this can help maintain their sense of identity, meaning and purpose (O) because the course generates opportunities for talk about self to reinstate identity (M)	CS3 observation fieldnotes: talk about animals about what makes them stressed. CS2 the FS thinking about birds and doing this activity with husband. Interviewer: Because she talked about some of the difficulties, didn't she, and she talked a bit about the sort of strategies that she'd come up with to cope. And I liked it because I think you laughed when she said <i>"taking the doors off"</i>. She got the screwdriver out, didn't she, and took the cupboard doors off in the kitchen? [so she could find things more easily] CS2.2-30 attendee with dementia: Well, I was in the building trade, you see, and I was a bricklayer/ plasterer. Interviewer: Oh, that's why it made you laugh. CS2.2-30: But I always wanted to be a joiner. And when I was when I was a young lad, this neighbour, her husband was a plasterer and he said, <i>"Oh, I'll take you for this interview [unintelligible]."</i> He said, <i>"I know [name]. He runs this apprentice scheme."</i> I sat down at the table and he was at the other side, <i>"Now then, young man," [unintelligible], "Now then, young man,"</i> he said, <i>"What do you want to be?" "Oh," I said, "I want to be a joiner."</i> And I did, I wanted to be a joiner because I was always good at woodwork.

Theme 2 Managing uncertainty for positive reframing: When tutors are skilled in working together, balancing input, and responding sensitively to verbal and non-verbal cues, especially when attendees express a range of emotions such as distress, tearfulness, or self-blame when recalling their diagnosis or on seeing others' distress (C) attendees feel emotionally supported and included (M) • meaning people feel able to remain in the Recovery College Session (O)

Context-Mechanism-Outcome-Configuration (CMO)	Data example/s
EVAL CMOC6 If people with dementia express a range of emotions when recalling their diagnosis or seeing others' distress (C) then skilled tutors who support each other can identify and diffuse situations in the moment and validate that person's experience (M) this creates a safe environment where people are able to share their experiences (O)	CS1-02 peer tutor with dementia: It just makes it easier to understand and to find a solution to it. So I think in that respect, I'm quite a useful person to that team as well because if I say so myself, I've got good interpersonal skills. I can diffuse a situation. I can give someone a bit of love if they need it. I can be a little bit stern if they need it and I can make them smile if they need it, and that's important to lighten the load on them. CS1-02 attendee family supporter: So I was worried that it would all get a bit over-emotional and I'd end up going, "Do you know what, I've got to get out of here," but it didn't at all. But when it did get emotional for a couple of people, it wasn't the sort of emotion that we couldn't handle. Yes, so this lady being upset, it was handled beautifully by the staff there and the doctors there. ...you will actually find, because I think I found there, that everyone there supported people that were upset. It wasn't they were just supported by the presenters, but actually, other people in the room supported them as well.
EVAL CMOC7 If staff and peer tutors can balance input from course attendees by redirecting back to others (C) then individuals won't dominate the conversations (M) enabling everyone to speak, contribute and not be interrupted (O)	CS3 observation fieldnotes: [the session] moves to a post-it note activity. We move to sit in groups of three which means there is a staff tutor, peer tutor or [researcher] with each dyad. Staff Tutor-02 gives out post-it notes and pens, the flip chart says 'What causes you stress?' We are asked to write down things that cause us stress. CS3-02 attendee family supporter says her husband struggles to decide on things, so when they go out for a meal, they look at the menu online beforehand so he can choose and not be stressed at the event. CS3-01 attendee with dementia [her husband] interjects that he does this, but mainly to see if the food looks good and if he wants to go, then complains about food when eating out. Staff Tutor-01 redirects back to CS3-02 and says what a great idea, think of other things for next week. CS3-06 peer tutor family supporter: One person on one previous course was very much, "I'm going to dominate the course and I'm going to tell you everything that's happened to me." And actually that's not helpful because everybody needs their own chance to speak and their own time to share their experiences and if somebody was just railroading in every time with me, me, me, that probably wouldn't help. I think the general thing is being aware of other people wanting to help them and empathetic to what they're doing. You need to have that empathy with what they're going through.
EVAL CMOC8 If there is too little time to cover planned content and the session falls behind (C) tutors may feel rushed to move things on (M) and this limits interactive time shutting down time for the attendees to contribute or to respond to emotions (O)	CS1 observation fieldnotes: The group are told this is time to think about concerns and Slide 12 indicates this is a paper exercise. The staff tutor moves to a chair next to an attendee with dementia as the family supporter peer tutor stands to lead this section, and asks if people are willing to share their score and then they will talk about concerns. CS1-09 attendee with dementia says "<i>I am confused</i>" and a family supporter attendee says in response "<i>oh bless you</i>" then says she feels frustrated and angry with her parents for not making arrangements, so now she cannot access parents business accounts and is waiting for a court of protection order. Another family supporter attendee asks her what to do if you can't get power of attorney and she explains why not in her circumstance. The staff tutor says that the family supporter peer tutor will cover that topic later. It appears she is trying to move the activity on. I note several times during the activity she says "<i>We need to move on, we are running a little behind time</i>". My [observer] impression: an urgency to stick to time meant that when attendees were talking and sharing experiences these

	conversation tended to be halted. CS4 observation fieldnotes: With minutes left, CS4-02 peer tutor family supporter introduces the issue of driving and dementia, telling DVLA and claiming Attendance Allowance, then <i>"I think that's about it"</i>. There is a sense of having to get all the information covered, even if done in a bit of a rush.
--	--

Theme 3 Connecting together enabling hope: When the person with dementia is empowered, often by family supporters, to engage in personal recovery activities such as peer tutoring or attending a course (C) they are able to connect with, and learn from, others with similar experiences (M) meaning people with dementia have a safe place to discover new meaning and value in their relationship and experiences (O)

Context-Mechanism-Outcome-Configuration (CMOC)	Data example/s
EVAL CMOC9 If people with dementia attending are offered extra help and time for greeting and settling in (C) then social nervousness can be abated to some extent (M) because attendees are more relaxed and connect through talking more amongst themselves (O)	CS3-03 peer tutor family supporter: The reason I say that is that the person with dementia is probably very anxious and very nervous. And if he or she has somebody with them who they know and love, that can only help them to settle down. I think that's the right thing to do. Sometimes it's difficult. We had one lady who came on her own, all you've got to do is make a little extra effort with her to make her feel comfortable because she hasn't got anybody alongside her. It is easy to do, all you have to do is chat, it's all about talking. CS2.2-13 attendee with dementia: I found it interesting. I enjoyed it. Yeah. It was enjoyable...It's just something different, you know... Just something different, yeah. Very friendly. Yeah. CS3-03 attendee with dementia: I think you feel apprehensive going and self-conscious about going don't you but I think it does you good. ... I didn't worry about going. I might have been apprehensive a bit the first week. You are aren't you, but – anything to help isn't it. And make you realise you're not alone. There's loads of people like you. It's not the end of the world. CS1-09 attendee with dementia: Yes. I was a bit concerned wondering, <i>"How can they help me?"</i> and, <i>"Will I be all right or will it change my life?"</i> but yes, it has. It's made me feel not guilty no more. Interviewer: So you talked about that change in how you felt, being about meeting other people with dementia in the room who were talking about their experiences. Was there anything else about the information that was being discussed in the room? CS1-09: Well, I felt warmth. Interviewer: So you felt warmth, a sense of warmth. CS1-09: Warmth and wanted, like they understood me and I thought, <i>"Well, somebody understands what I'm going through,"</i> and that means a lot to somebody like me.
EVAL CMOC10 If the course begins with a warm-up activity that is non-dementia related (C) attendees do not feel compelled to share anything emotive or identify their dementia status (M) because the course is seen to be a positive and inclusive shared learning environment (O)	CS3 observation fieldnotes: Staff Tutor-01 had made a series of slides with animals and questions all related to the animals people had spoken about in the warm-up activity from the session last week. The first slide asked <i>"Who has a goldfish?"</i> No-one answered until ST-01 looked at the dyad CA-03 person with dementia and CA-04 family supporter saying <i>"I thought you said you had a goldfish?"</i>. CA-04 said no it was their children who had had a goldfish, ST-01 responded <i>"Ah you had a goldfish in the house"</i>. CA-03 then spontaneously spoke and said they couldn't have a cat because of the road. It was noticeable that in this session, CA-03 spoke much more within the group with snippets of her life. CS3 observation fieldnotes observer impressions: Set up that warmed people up for sharing and did not put people in a position that they could not contribute to, or in a category. CS3-01 attendee with dementia/dyad with CS3-02 family supporter interviewed together. Family supporter includes spouse in her comments. Interviewer: And one of the things I noticed was that at the beginning of every session we talked about animals or your crows and things like that. CS3-01: Oh right, I know the one you're talking about. That was neat that was. You could say something and have a little laugh you know. CS3-02: We've always been very open haven't we?

	CS3-01: Yeah, in a way we've either got it or we haven't basically. But not saying that I don't want to bother about it, I'd like it all to come back again. CS3-01: – to get there. Now I made them laugh when they were on about the stick and things. I said, <i>"Well I'm sorry but I didn't know about that. I can tell you about these pigeon things."</i> To get out of the way of what I'm not getting. [Laughs]
EVAL CMOC11 If there is time for informal conversations, for example during ice-breakers and tea breaks (C) course attendees can better connect with each other (M) because informality contributes to creating a safe space for talking more openly during course sessions (O)	CS3 observation fieldnotes: During coffee break CA-03 and CA-08 attendee family supporters were chatting together about CA-03 having high standards but can no longer do housework to the standard they want. CA-08 gave a sense of understanding and empathy. I think they probably bonded after recognizing a shared interest in group conversations. CS1-02 peer tutor with dementia: We could have done that through an ice-breaker and that would have got people talking a little bit about themselves. I always have an ice-breaker if I do a presentation. I think that works wonders for people. It relaxes them a bit and you can find out if there is anything that's really bugging them. Also, who the loud mouths are, etc. CS3-01 attendee with dementia: Oh right, I know the one you're talking about. That was neat that was. You could say something and have a little laugh you know. CS3-02 family supporter attendee: I felt very comfortable, I think because we had tea and coffee when we went in and what not. CS1 observation fieldnotes: I ask <i>"This is quite a large group?"</i> and she says yes and they are more talkative than usual groups explaining usual groups sit and listen then talk during the discussion bits. There is generally chatting during the coffee break. CS3-06 peer tutor family supporter: I just think in the room everybody can easily see people that haven't had a chance to speak yet. CS1-01 peer tutor with dementia will draw somebody in and say, <i>"How do you feel about that?"</i> I think you'd miss that on Zoom. Also it may be a bit of a bizarre thing but you'd miss the coffee breaks and we have really good conversations in coffee breaks. We will find out, we'll talk to people and people are open and much more likely to say something that's concerning them or something they might think it's silly and don't want to say in front of anyone else. All sorts of things have come out of previous groups in the coffee break haven't they. We'll talk about all sorts with people and you'd miss that. Interviewer: Yes, that's one of the things I noticed [while observing] at the session, that there was a lot of chat at the beginning when we all got a cup of tea before we sat down. And then a nice long break in the middle for a chat and everybody was moving around and talking. And that felt comfortable, people felt comfortable. CS3-03 peer tutor family supporter: It gave people time to think as well.
EVAL CMOC12 If there is space for discussion and debate in the wider session and/or in small groups (C) attendees can learn things from each other (M) this brings about higher levels of interaction and shared engagement with the learning materials (O)	CS2.2-12 attendee family supporter: It's just that we didn't have much debate. I mean, there was a comment made, wasn't there, that sometimes there's a lot fewer people in the room and they have discussion groups. And going back in my experience, the things I've been involved in historically, that was always useful to have discussion groups going on around tables and, you know, feedback coming from the discussion groups on issues. And I think that you probably use that, don't you? CS3 observation fieldnotes: [learning material – 10 minute video] Video made by [name of peer tutor with dementia not present]. Introduced by lead staff tutor and acknowledged that this person and their wife had developed the course but were no longer able to attend as too busy. Gave overview of the video and instructions for what to look out for, preparing people for the group discussion and enabling them to contribute. Video discussed the reality of diagnosis with some very emotive material shared and dark places that [name] had been to. Then the video became more positive as [name] reported finding his purpose. Co-lead staff tutor then led discussions by inviting reactions to the video that were recorded on a flipchart. 11

	(her) smiles and shares thoughts about findings purpose which lead staff tutor builds on. 2 is very emotional after the video despite having seen several times in previous courses. She discusses her reaction with the group which the staff tutors help to defuse. They acknowledge the difficulties. 10 is checking the flip chart. 7 emphasizes the need for self-motivation and thinking differently, explaining what the challenges are for her and how she needs to think differently about how to go about things she enjoys, maybe participating in a different way. This encourages an exchange between some of the members of the group who are validating each other's experiences. There is quite an exchange where the group acknowledges that the person doesn't change but need to change what/ how involved in things including 13 who didn't always overtly participate. CS4-01 staff tutor: We shortened it to make it more discussion based. Because it was online we had to miss out some of the stuff that we'd have done in a face-to-face group. But I think that was good. And now, when we bring it back face-to-face, [we] probably won't add a great deal to create space for discussions. ... The Recovery College model, you know, the actual ethos of them, we actually, you know, we get, you know, the experts by experience and the people in the Recovery College saying "This is what they need," so we shortened it and that worked out really well. So it did change in that way but that was a positive thing. Because I think sometimes as professionals we hide behind presentations and PowerPoints. I think as I've become older and more experienced, I put less slides in so they've time for the discussion and I run the slides off. I think that was quite beneficial really. CS1-02 peer tutor with dementia: A lot of people there had stories that they wanted to tell, they were bursting to tell and we didn't have time to listen to them. Listening to them is as important as telling them, and I know we weren't there for a therapy session, but look, anything like that tends to turn into one. Everybody there has got a story and they want to tell it, and if you don't let them, the danger is that they'll lose interest in what you're trying to say, because really, there might be umpteen different types of dementia out there, but it's a lot to take in, especially if you've only just been diagnosed a week or two before.
EVAL CMOC13 If people with dementia find it difficult to actively contribute to the course through conversation or activity (C) then they may still experience a sense of connectedness with others and the learning activities (O) because they are watching and listening (M)	CS1 observation fieldnotes: CS1-07 attendee with dementia sits quietly looking forwards and sipping cup of tea. ... is looking ahead there is no emotion on her face but she seems to be listening. ... I note that CS1-07 is awake at all times and looking ahead but is not contributing at all. CS3-01 attendee with dementia/dyad with CS3-02 family supporter interviewed together. Family supporter includes spouse in her comments. CS3-02: But I watched CS3-01 to make sure he's OK and the thing I did notice which I felt was really important, he had his attention the whole time. You were really engaged with it. So it must have been of interest to CS3-01 because there wasn't a time when I saw him zoning out, which you can do sometimes. So you were very comfortable there weren't you. CS3-01: Yeah it was fine being there all the time. If halfway through it you think, "Oh god we've got to get on with this again, blah, blah, blah," then they're likely to squeeze out through the door or something or start saying – CS3-02: That didn't happen did it. Interviewer: You said that you really enjoyed meeting other people in the same situation as you. Did it change the way in which perhaps you thought about your own diagnosis at all? Did it change the way in which you thought about things? CS3-03 attendee with dementia: No I don't think so, that was just nice. I suppose it's just nice. There was a group of people there that are the same as you. Interviewer: Was there anything you didn't like at all about the course where we were all sitting round the table and the videos were playing and people were talking and that type of thing? Anything you didn't like? CS3-03: No. I'm pretty easy going really. I just take it as it come really.

	Interviewer: That's great. CS3-03: It's all done for your benefit, that's what I think, to help you. Perhaps some things might not apply to you so much as others. But you have to hear the whole thing don't you. CS2.2-13 attendee with dementia: I found it interesting. I enjoyed it. Yeah. It was enjoyable. Interviewer: What about it was enjoyable? CS2.2-13: It's just something different, you know. Just something different, yeah.
EVAL CMOC14 When people with dementia attend courses co-facilitated by a peer tutor who also has dementia and who focuses on reclaiming a positive life after diagnosis (C) this helps people believe there is hope when living with dementia (M) because connecting with peers who share lived experience fosters hope and optimism about managing dementia positively (O)	CS3-03 attendee with dementia/dyad with CS3-04 family supporter interviewed together. The person with dementia includes spouse in her comments. CS3-03: The main thing I thought was it would be nice to meet other people who are in the same position as me, whose memory is not as good you know. You know you've not got two heads or anything like that sort of thing. I mean that's why I thought that was nice. My main reason I thought that was nice, that's good for CS3-04 as well to meet others, for both of us really. See how other people cope with it. I mean I'm glad I went, that was – I needed to meet other people with the same. Interviewer: So did it meet that, there were a few other people living with memory problems, was that helpful for you? CS3-03: Yeah, I suppose the general atmosphere was the same really wasn't it. You felt like a group of people in the same position didn't you. Interviewer: Yes, that word atmosphere is quite interesting. How did it feel for you then? CS3-03: Yeah, you feel a bit apprehensive when you go the first time. Otherwise I didn't really worry and I didn't notice any tension, did you CS3-04? CS3-04: No
EVAL CMOC15 If people with dementia attending a course can see and hear other's lived experience of dementia (C) they learn they are not alone (M) therefore people experience a sense of connection, belonging and solidarity (O)	CS1-09 attendee with dementia: As I said, when I came there, I was scared. I really was scared and I didn't know what to do. I was listening. It was very interesting and then I thought, "Right, I will have my say and I will tell them." Now I met people there, I know all them, what's got dementia – ... Because I wanted help. I wanted to put my mind clear, what I thought dementia was, and I want to put that clear, and then when I met these people there, I knew it wasn't my fault. I haven't done nothing wrong and I've got that to thank for, and I told my son. Interviewer: So was there anything from this morning that's helped you particularly. Was there anything that stood out? CS2.2-30 attendee with dementia: Well, yeah, listening to her mainly talking about her experiences, and that, and, well, the fact that I looked out and I could see there's others that are obviously in the same boat as me, as you might say. CS3-03 attendee with dementia: The main part that I like is it was really seeing how people like me have got bad memory's. I think that does me more good, I don't feel so, you know. It's mixing with people isn't it. You don't know them do you but you sit near them and you chat don't you. I think that is a good tonic. ... To go and you know have other people, you're not such a freak you're just a bit of memory loss. Which when you're nearly 90 what do you expect?
EVAL CMOC16 If the peer tutor with dementia connects with attendees who may be shy, embarrassed, or face cognitive challenges (C) then attendees will be more comfortable participating and sharing their experiences (O) because attendees are empowered to contribute (M)	CS2-02 peer tutor with dementia: Well just it gives me a chance to talk. It gives me a chance to show people that people with dementia can talk. Again when I'm a room I can ask people, "What did you expect when you came in?", it's not quite the same online. You know, "What were you expecting me to be like knowing that it was somebody with dementia delivering the course?", it doesn't work the same. I don't get the same feedback as I do face to face. But I wouldn't do something if I didn't love it. CS1 observation fieldnotes: A powerful moment was when the staff tutor called the group together to enable the voice of the person with dementia who was previously distressed to be heard, describing how different and better she felt having joined this group today. The person makes the statement <i>"before I came here I was</i>

	<i>blaming myself - now I am not blaming myself”.</i> CS2.2-22 attendee family supporter: The honesty of what people said. There was only a couple of people mentioned things – a gentleman at the front about his father. The honesty of how it came out, how it came over, it’s good, it gets something off your chest. And I probably should have said something myself, but it’s difficult. How do you handle it? And I don’t know to ask the question, to be truthful. I didn’t want to let myself look a fool, and I’m not really clever enough. I’ve never been clever enough in my life to ... I’ve achieved some things, but not to the heights of what my wife has. I think we’ve all done it in our own way, haven’t we? I’ve travelled part of the world and got on with my job, but to stand up in front of a group of people and asked a question that they might think silly, it frightens me, so I didn’t bother.
EVAL CMOC17 If people with dementia are struggling and still adjusting to their diagnosis (C) peer tutors genuineness through sharing their own lived experience can quickly connect with attendees (M) this fosters hope for a positive life with dementia (O)	CS1-02 peer tutor with dementia: I believe that my dementia, my diagnosis of dementia and the life I’m living now has given me a perspective that is useful to Recovery College. I think it’s gifted me with, my lived experience has gifted me with the ability to actually speak to people who have just been diagnosed with a voice that is unique and can’t be – I can tell them things that a practitioner can’t tell them and I can get away with it because I’m there, I’ve been there. I’m in the same boat as them. And I think that, so I can be a role model even, I dread to think I’ve ever been one of them, but I think I can be because here I am standing up in front of them. CS2.2 observation fieldnotes: The session then began with the peer tutor with dementia introducing herself and talking at some length through her lived experience of being diagnosed with young-onset dementia and her view that clinicians know so little about living with the condition “I was so shocked at the lack of awareness” “I was so shocked about the negative manner of the diagnosis process – all about negative language”. The neurologist said “there’s nothing we can do”. “Do not underestimate the words and body language used”. She talked about being given a sense of “no hope” but wants to change the narrative to focus on what people can still do, not what can’t. talks about the lack of, at the point of her diagnosis, the word hope, in any of her conversations or written information. She thinks the term ‘living well’ is a bit of a problem, as it sets a high standard, might not be achievable for many, on every day, or at all, as living with dementia brings despondent days; “it’s a bummer, but we can still enjoy life if we concentrate on the better/good days. Again, we need that little 4-letter word – HOPE – we need to hear this”. (Researcher reflection: I also wondered if this was a message about acceptance and being kind to yourself on the ‘bad’ days). This is described as being in relation to being offered a more hopeful message about living with dementia at the point of diagnosis. The attendees are listening and focused. CS2.2-30 attendee with dementia: Well, mainly listening to what she was saying and what her experience is, and that...Well, it makes me think of if I get worse, which I maybe will do – we don’t know – it gives me a general idea of what to expect. You know what I mean? CS2.2-31 attendee family supporter: I tend to go into these things with a completely open mind, so I didn’t know what I was going to see and certainly Dad wouldn’t have known what he was going to see, but I just thought that there would be, some positives would come out of it, we would hear about things that we didn’t know about and maybe be able to contribute with things that might help others. CS3-05 peer tutor with dementia: I don’t think of myself as a tutor, no, I’m just somebody who hopes to help people. I just want to – when we first got the thing. [CS3-01] staff tutor went in and she was chatting away and I thought, “Well what’s next.” And then that did come out didn’t it, that there is a next, but that was a little bit longer because they’d got to put the whole thing together hadn’t they. So I think that’s lovely.

EVAL CMOC18 If peer tutors with dementia share their own experiences of finding ways of living positively with dementia despite the difficulties (C) this resonates with and empowers attendees (M) and there is connection and shared learning (O)	CS1-02 peer tutor with dementia: I want to fire people up with enthusiasm and show them the benefits of doing all of these things and how they will impact their future and also how it will help their loved ones and their circle of friends and families later on. These are the decisions people put off and don't want to face, but they must face. So that's the important thing for me. ... I also see a role for myself as someone with lived experience, someone who's living with dementia but is still able to speak. Speaking to professionals too to say, you know, "This is me. I'm not someone that you do things to. I'm not an object to pity. I am a reasoning, functioning human being. Sometimes I have trouble expressing myself, but here I am," just to let people know that sometimes the person that they perceive someone to be is not that person at all. We are <i>compos mentis</i>. Interviewer: What did you think about his presence as a trainer and a tutor there on that group? CS1-09 attendee with dementia: I thought it was good because it's going to show ... I've got to put this right. It's going to show the dementia people that they can do things. I mean, a lot of people think, "Well, I can't do nowt' because I've got dementia," like me, but when he spoke and he said he was doing it, and it was like I thought, "You must have been really brave," and that's showing us lot that we can do things ourselves as well. We don't need to depend on everybody. CS1-09 attendee with dementia: You don't need to think, "Oh, I've got to have you to help me because I've got dementia." Interviewer: So seeing him in that position, standing at the front of the room and – CS1-09: And talking and that. Interviewer: Talking and presenting, yes. CS1-09: Yes, I thought he was very brave. I don't know if it's helped anybody else, but it's made me think, "<i>You can do things yourself if you want to, but you've got to put your mind ...</i>" It's like knitting. Some people wouldn't knit because they don't put their mind to it. You put your mind to something and try to block this out, it can help and I've never been so happy since I've been there. Interviewer: Anything else that you've heard this morning that sort of rung a particular chord for you? CS2.2-28 attendee with dementia: Just about everything, really. I just sat and listened and ... No, it was very encouraging, I thought, but I'm not going to skydive. [Laughs] CS2.2-29 attendee family supporter: I found that [peer tutor with dementia] concentrating more on the positive side and how to do things ... I wasn't quite sure at first whether it would be all doom and gloom and, really, I thought if it's going to be like that, I didn't want my mum to come, but I wanted to know about it. But I found it so positive. It was so nice and I'm so glad that my mother did come because it's sometimes second-hand information if I'd have told her, she probably wouldn't have believed me. Yeah. CS2.2-07 attendee staff: There was a man who asked a question about how dementia can affect your speech, and I know this is something that has impacted [peer tutor with dementia] when she was giving the talk. They had a conversation, and it was really nice to see the connection that they could make with each other and how they could understand where the other one was coming from because it's something that impacted them both, obviously in different ways. I don't know, it was just nice to see that this man felt seen and heard by somebody who is actually experiencing what he's experiencing.
EVAL CMOC19 If an attendee does not recognise their experiences in the course content and discussions (C) then attendees may not feel they have	CS4-01 attendee family supporter: It was good talking to other people but I think some people's parents or partners were more advanced than mum. And I'm not sure, it was interesting, but I'm not sure I got out of it really anything for me, yeah. CS2.2-21 attendee with dementia: And I just had nothing but admiration for her

learned anything (O) because they find these difficult to relate to (M)	because you can see by the way she's going that it's beginning to affect her a lot more, but she knows exactly what she wants to get over and how. I think she's a wonderful lady, but I cannot take much away because I don't know what sort of dementia she has, but it doesn't seem as if it's my sort. ... I obviously didn't bring it out yesterday about the hallucinations that I get. I don't think I recall her at any time saying that she had that sort of thing. ... But I would love to meet somebody that does [laughs] and how they get around it or what they do. Because sometimes on a night, it's quite frightening. ... I don't know what I expected out of yesterday. And I suppose seeing [peer tutor] there, sort of, "Oh, [peer tutor]." [Laughs] So it sort of calmed me down a bit, but I still come away thinking, "What have I got?" ... I don't know. I found that I didn't think it related to me specifically or my type of dementia specifically, but I look around and I think, "Where do I fit in?" And it is difficult to know where you fit in in those cases. I would have liked it to have come out and smacked me around a bit and said, "This is where you fit in," but it didn't happen. ... Well, I don't know how, because if you're ... I mean, we're all different, aren't we? So even if you had us all sat together and said, "Oh, that group there, they've got dementia," it still wouldn't work.
EVAL CMOC20 If course materials include culturally diverse stories, references and activities (C) then this will support discussions, make meaning of and increase acceptance of dementia in cultural minority groups.	CS1 staff tutor: I do have used particularly, you know, coming from ethnic minority myself. I would. I would like, you know, people from my background or other ethnic groups to participate. ... And I'm not certain whether we are actually including within the teams sort of cultural competency. I think I do it on an individual basis. CS4 CA-01 attendee family supporter: My mum remembers when she's younger. I can't share [these memories] with her because I mean, I know you can't share with what you've only heard. But if my mum was born in [Caribbean], we were in [UK city] and I was born there and now we live [UK town]. I could probably take her to [former UK city] but, I can't take my mom to [Caribbean] and take her around. I raised that in the course that aspect of not being able to share those memories [as they advised].