



## Synopsis

# Recovery Colleges for post-diagnostic dementia support: The DiSCOVERY realist evaluation synopsis

George Christopher Fox<sup>1\*</sup>, Juniper West<sup>2</sup>, Thomas Rhodes<sup>2</sup>, Fiona Poland<sup>3</sup>, Linda Birt<sup>4</sup>, Melanie Handley<sup>5</sup>, Geoff Wong<sup>6</sup>, Esme Moniz-Cook<sup>7</sup>, Emma Wolverson<sup>8</sup>, Bonnie Teague<sup>2,3</sup>, Corinna Hackmann<sup>2</sup>, Rachael Litherland<sup>9</sup>, Leanne Hague<sup>2</sup>, Jarin Alam<sup>2</sup>, Kathryn Sams<sup>2</sup> and Ruth Mills<sup>2</sup>

<sup>1</sup>Department of Health and Community Sciences, Faculty of Health and Life Sciences, Faculty of Health and Life Sciences, University of Exeter, Exeter, UK

<sup>2</sup>Research Department, Norfolk and Suffolk NHS Foundation Trust, Norwich, UK

<sup>3</sup>School of Health Sciences, University of East Anglia, Norwich, UK

<sup>4</sup>School of Healthcare, University of Leicester, Leicester, UK

<sup>5</sup>Centre for Research in Public Health and Community Care, University of Hertfordshire, Hatfield, UK

<sup>6</sup>Nuffield Department of Primary Care Health Sciences, Medical Sciences Division, University of Oxford, Oxford, UK

<sup>7</sup>Faculty of Health Sciences, University of Hull, Hull, UK

<sup>8</sup>The Geller Institute of Ageing and Memory, University of West London, London, UK

<sup>9</sup>Innovations in Dementia CIC, Exeter, UK

\*Corresponding author [christopher.fox@exeter.ac.uk](mailto:christopher.fox@exeter.ac.uk)

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## Abstract

**Background:** Recovery Colleges offer peer-led, coproduced psychoeducational courses to support people to have meaningful lives. There is limited knowledge of their use in the context of dementia. This study used a realist programme theory approach to develop an in-depth understanding of how United Kingdom Recovery College dementia courses lead to outcomes for people with dementia, families and staff.

**Objectives:** To build knowledge through mapping Recovery College dementia courses across the United Kingdom; conduct a realist review of evidence; identify key components of effective Recovery College dementia courses within a realist programme theory; identify outcome measures for evaluating Recovery College dementia courses; understand diverse ethnic and cultural needs of people with dementia in accessing Recovery College dementia courses; and coproduce resources for implementing Recovery College dementia courses

**Design and methods:** A mixed-methods design to examine what works for who and in what circumstances, coproduced with people with lived experience of dementia and staff from National Health Service Recovery Colleges and memory services. This involved: a United Kingdom-based staff survey of memory services and Recovery College dementia course provision, delivery and attendance; a realist review combining literature and stakeholder knowledge to build an initial programme theory; a realist evaluation using ethnographic observation within five case studies, realist interviews and documentary evidence, with analysis involving stakeholders using realist logic to explore causal processes operating in different contexts and intended and unintended outcomes (i.e. Contexts, Mechanisms and Outcomes); a scoping review of potential outcome measures for evaluation; and coproduced resources using three rounds of stakeholder workshops.

**Setting and participants:** Set in United Kingdom National Health Service mental health organisations, staff recruitment from Recovery Colleges and memory services and people with dementia/families from Recovery Colleges.

**Results:** Twelve (from 51) Recovery Colleges offered dementia-specific courses, and 210 memory service staff completed the survey. Thirty-five documents and discussions with 19 stakeholders (7 people with dementia, 2 family

carers, 10 staff) informed the initial programme theory. A trusted person endorsing a course encouraged attendance. Shared coproduction values underpinned the success of setting up and running courses. Through co-facilitation of recovery-focused content by peer-tutors with well-developed facilitation skills, attendees appeared to mediate self-stigma, manage emotional uncertainty and make meaningful social connections in ways which engendered hope for the future. Course evaluation was challenging as people often left without completing a written survey. One attempt at pre and post course well-being measures failed to capture follow-up date.

**Limitations:** Four case sites were recruited, limiting diversity in course delivery methods and participant backgrounds. Numbers of people with dementia attending courses was lower than expected, raising questions about awareness and accessibility. Course evaluation was limited to standard feedback sheets. Sufficient data on coproduction processes and staff experiences were lacking, thus restricting refined theories about coproduction and its impact on practice.

**Conclusions:** Recovery-focused post-diagnostic courses can enable people with dementia to consider a hopeful future. Resources available may stimulate inclusivity and accessibility. The authenticity of peer tutors with dementia resonated with course attendees, and lived experience insights from people who were living positive lives with dementia is a key strength of this form of post-diagnostic support.

**Future work:** Longer-term outcomes (e.g. hopefulness) for people with dementia attending recovery-focused courses is possible, but further validation of identified measures to address responsiveness, interpretability, inclusion of personal-recovery domains and cultural sensitivity for diverse populations is a pre-requisite.

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A plain language summary of this synopsis is available on the NIHR Journals Library Website <https://doi.org/10.3310/GJCF2730>.

## Introduction

This study focused on experiences of coproducing and attending peer-led, psychoeducational courses about dementia. This is an emerging method of post-diagnostic dementia support within Recovery Colleges in mental health organisations in the UK. Full details of methods and findings are reported in our other publications (*Table 1*) and are summarised in *Methods* and *Results*.

## Background

Receiving and adjusting to a diagnosis of dementia is life-changing for the person and their family, bringing many uncertainties compounded by social stigma.<sup>1</sup> Patient and public involvement and engagement (PPIE) advisors for this project – from a local group of people with dementia and their family supporters, reported feeling unable to disclose their diagnosis to others, which was made worse by the prevailing negative attitudes in society around dementia and ageing.<sup>2</sup> The progressive nature of dementia in limiting communication and cognition more broadly brings anxieties for people trying to preserve identity and confidence in roles, relationships and interactions. These factors contribute to people with dementia becoming disempowered, silenced and marginalised.<sup>2</sup> Yet, people living with dementia in all stages may retain self-awareness and ability to maintain their social connections, challenge stigmatising stereotypes and actively engage in shaping their experience of dementia.<sup>3</sup>

The post-diagnosis period is critical to support adjustments to individual needs as they change.<sup>4</sup> Most people are

assessed and diagnosed within NHS mental health memory services, and following this process, they should expect flexible access to a range of specialist support that is tailored to meet individual specific needs.<sup>5,6</sup> While some people do receive this, there is a significant variability in the quality, duration and eligibility of post-diagnostic dementia support across the UK, and what support there is generally remains poorly defined or evidenced.<sup>7-9</sup> Additionally, unintentional messaging focused around cognitive deficits can disempower people and cause distress, for example, advice on stopping driving and arranging powers of attorney can result in the person 'giving up life as they know it', defined as 'Prescribed Disengagement™'.<sup>10</sup>

Collectively, these issues can reinforce feelings of isolation and loss, therefore undermining engagement of people living with dementia and their family in finding ways to live 'well' with dementia. PPIE advisors told us their experiences were of families being left largely unsupported in finding out what the person with lived experience might need and having to self-navigate through health and social care services without knowledge of likely immediate or long-term needs. This experience is supported by research, which has found psychiatrists saying they are limited in their ability to discuss well-being and living well with people they were diagnosing with dementia because of the lack of services available to offer this kind of support.<sup>11</sup> A survey of dementia care co-ordinators found that they saw offering post-diagnostic services to people with dementia from diverse ethnic and cultural backgrounds as 'challenging', with little provision to mitigate language or cultural barriers.<sup>12</sup> A further study found that people

TABLE 1 DiSCOVERY study publications

Date	Publication
2019	Lowen C, Birt L, West J. Recovery Colleges and dementia courses – a scoping survey. <i>Ment Health Soc Incl</i> 2019;23:166–72. <a href="https://doi.org/10.1108/MHSI-08-2019-0024">https://doi.org/10.1108/MHSI-08-2019-0024</a> <sup>13</sup>
2022	West J, Birt L, Wilson D, Mathie E, Poland F. 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. <i>Front Rehabil Sci</i> 2022;3:920496. <a href="https://doi.org/10.3389/fresc.2022.920496">https://doi.org/10.3389/fresc.2022.920496</a> <sup>14</sup>
2023	Birt L, West J, Poland F, Wong G, Handley M, Litherland R, et al. Protocol for a realist evaluation of Recovery College dementia courses: understanding coproduction through ethnography. <i>BMJ Open</i> 2023;13:e078248. <a href="https://doi.org/10.1136/bmjopen-2023-078248">https://doi.org/10.1136/bmjopen-2023-078248</a> <sup>15</sup>
2024	Wolverson E, Hague L, West J, Teague B, Fox C, Birt L, et al. Building an initial understanding of UK Recovery College dementia courses: a national survey of Recovery College and memory services staff. <i>Work Older People</i> 2024;28:108–19. <a href="https://doi.org/10.1108/WWOP-02-2023-0003">https://doi.org/10.1108/WWOP-02-2023-0003</a> <sup>16</sup>
2024	Handley M, Wheeler C, Duddy C, Wong G, Birt L, Fox C, et al. Operationalising the Recovery College model with people living with dementia: a realist review. <i>Aging Ment Health</i> 2024;28:1078–89. <a href="https://doi.org/10.1080/13607863.2024.2356878">https://doi.org/10.1080/13607863.2024.2356878</a> <sup>17</sup>
2025	Alam J, West J, Moniz-Cook E, Wolverson E, Handley M, et al. A scoping review of outcome measures for people living with dementia and family supporters to evaluate Recovery College dementia courses. <i>Front Psychiatry</i> 2025;16. <a href="https://doi.org/10.3389/fpsyt.2025.1591772">https://doi.org/10.3389/fpsyt.2025.1591772</a> <sup>18</sup>
2026	Birt L, Handley M, West J, Alam J, Poland F, Moniz-Cook E, et al.; DiSCOVERY study team. Role of peer-tutors with dementia in Recovery College dementia courses: an ethnographic account. <i>Gerontologist</i> 2026 Feb 15:gnag010. <a href="https://doi.org/10.1093/geront/gnag010">https://doi.org/10.1093/geront/gnag010</a> <sup>19</sup>

from diverse ethnic and cultural backgrounds were less likely than White British groups to be offered or use post-diagnostic community support for dementia.<sup>20</sup> This meant post-diagnostic support often fell predominantly to the families of people with dementia from diverse ethnic and cultural backgrounds.

Coproduction in health care involves working together with patients and staff in different ways depending on the situation, and it tends to lead to better patient experiences, more efficient services and improved health outcomes.<sup>21</sup> This approach combined with peer-led psychoeducation is flourishing in adult mental health services, encouraged since 2011 by the Department of Health-commissioned Implementing Recovery through Organisational Change (ImROC) collaborative (<https://imroc.org/>; accessed 25 February 2025). Complementing clinical services, a recovery-focused, adult learning approach aims to improve care outcomes beyond a narrow focus on symptom reduction to help people rebuild meaningful, satisfying lives despite limitations caused by mental health difficulties.<sup>22</sup> Five interconnected conceptual processes of 'personal recovery' known as the CHIME framework underpin the term recovery in this context: Connecting with others, inspiring Hope, maintaining a positive Identity, finding Meaning in life outside of symptoms and Empowerment and control over life with a focus on strengths.<sup>23</sup> Working with mental health organisations,

ImROC founded Recovery Colleges that have rapidly become a core part of mental health services. As of 2021, there were 88 Recovery Colleges in the UK,<sup>24</sup> with the model replicated internationally.<sup>25</sup> However, Recovery College provision, while predominantly within statutory mental health delivery, is orphaned from commissioned NHS diagnostic and treatment services.

A typical Recovery College offers a number of psychoeducational courses on mental health and personal recovery, designed to increase attendees' knowledge, skills and confidence in self-management of their own mental health and well-being. Courses range from one-off sessions to several sessions spread over a number of weeks. All are coproduced and co-facilitated by peer tutors – that is, people with lived experience – together with healthcare staff. Peer tutors prepare for their role through having training to teach and support, and they receive supervision to ensure any sensitive issues can be supported effectively. Recovery Colleges use language that aims to empower attendees and place everyone involved at an equal level. Since the coronavirus disease discovered in 2019 (COVID-19) pandemic, many Recovery Colleges have also delivered content remotely via online video platforms. Unlike other areas of mental health service provision (e.g. therapeutic groups), courses are generally open access, enabling people with lived experience, family or friend supporters and healthcare

staff to self-enrol from a prospectus without having to go through any referral system.<sup>26</sup> Dedicated Recovery College staff help people to connect with peers, develop individual learning plans and support enrolment on courses to address individual care needs with more hopeful messages and meaningful priorities with which people can identify. Recovery Colleges' courses and content may vary, however, they systematically reference and apply the CHIME framework<sup>23</sup> and recovery principles of coproduction in involving and empowering people with lived experience and peer support in all aspects of course design and delivery.

Recovery Colleges have an important role in service improvement and individual staff knowledge, skills and practice development through opportunities to learn directly from lived experience by attending courses and developing skills in coproduction. The Francis Inquiry<sup>27</sup> highlighted professional disengagement, where clinicians are not placed at the fore to promote change, which can lead to accepting poor standards of care. By contrast, staff involved with Recovery Colleges report renewed motivation and positive impact on how they view their organisation,<sup>28</sup> greater capacity to see strengths and potential, and they develop positive attitudes to recovery and new skills to support patients' self-management.<sup>29</sup> Staff note the inspiring role of peer tutors within Recovery Colleges and the novel perspectives individuals bring through knowledge of lived experiences.<sup>30</sup> Importantly, this creates possibilities for changing attitudes, challenging 'them and us' cultures and tackling stigma and discrimination in the mental health system and beyond.<sup>30,31</sup>

### Rationale

A project identifying research priorities in Older People's mental health services ranked a question -11/26- emphasising a need for knowledge to reduce potential feelings of abandonment, shame, guilt, despair and hopelessness, which are often experienced by people with dementia and their family supporters following a diagnosis.<sup>32</sup> Through ongoing dialogues, we worked with people with dementia and staff working in memory services who were coproducing Recovery College dementia courses to codevelop the Theory of Change referenced in the realist review for this study.<sup>17</sup> This work enabled us to identify aspects of the Recovery College model that may to go some way to meet these needs. The CHIME framework for personal recovery,<sup>23</sup> operationalised within mental health organisations through Recovery Colleges, aligns with policy frameworks for person-centred dementia care,<sup>5</sup> national accreditation programme standards for memory services<sup>6</sup> and the National Dementia Strategy objective to develop peer support and learning networks.<sup>33</sup>

### Research question, aims and objectives

#### Research question

What factors support the coproduction and successful delivery of Recovery College dementia courses: what works, for whom and in what circumstances?

#### Aim

This study aimed to develop a sufficiently in-depth, evidence-based understanding, captured in a realist programme theory, of how existing mental health service-delivered Recovery College dementia courses and post-diagnostic support structures lead to intended and unintended outcomes for people living with dementia, their family supporters and healthcare staff.

#### Objectives

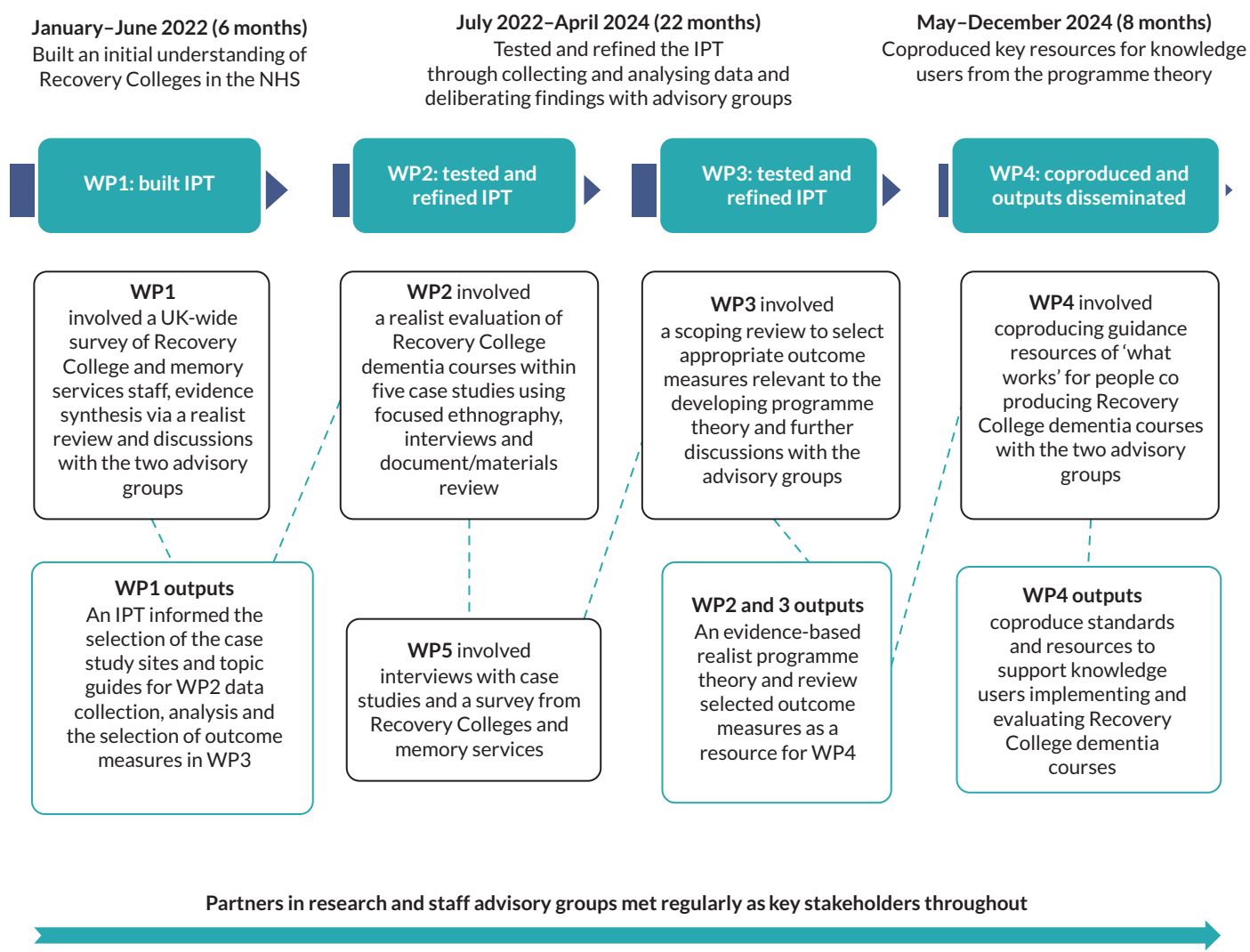
- 1 To map provision and build understanding of Recovery College dementia courses across the UK.
- 2 To conduct a realist review of evidence.
- 3 To identify the key components of effective Recovery College dementia courses in a realist programme theory.
- 4 To identify outcome domains and outcome measures that could be used to measure the impact of Recovery College dementia courses.
- 5 To understand the needs of people with dementia from ethnic and cultural minority groups in coproducing and/or accessing post-diagnostic support within Recovery College dementia courses.
- 6 To coproduce best practice guidance for implementing Recovery College dementia courses.

### Methods

Full details of methods and findings are reported in our published papers ([Table 1](#)) with the workflow through individual work packages (WP) described here and summarised in [Figure 1](#).

#### Establishment of stakeholder advisory groups

Methods and findings across all WPs were coproduced alongside key stakeholders, involved throughout the whole study from inception to dissemination. Two groups were established: one a PPIE group of people with dementia - this group established a preferred name: the DiSCOVERY 'Partners in Research' group; the other was with NHS Recovery College and memory and dementia services staff, ensuring that knowledge from lived and learned experiences of dementia and Recovery Colleges were embedded throughout the study. Some members of



**FIGURE 1** Summary of WPs and data flow. IPT, initial programme theory.

both groups had experience of coproducing or attending Recovery College dementia courses.

Within the Partners in Research group, 10 people with lived experience of dementia who had experience of attending or peer tutoring on dementia courses were recruited on a rolling basis. Initially, the group comprised of eight people with dementia, two alongside their family supporters; however, this changed during the course of the study, which is described in further detail in [Discussion](#).

Seventeen healthcare staff were recruited into the DiSCOVERY staff advisory group also on a rolling basis. This group was made up of occupational therapists, doctors, support workers, assistant practitioners and psychologists – and some who were service managers – working with older people in memory and dementia services, or in Recovery Colleges. Seven meetings were held with the staff advisory group.

### **Work package 1a: staff survey methods**

The WP1a involved an online survey of healthcare staff working in NHS mental health service-provided Recovery Colleges and associated memory services across the UK to gain a deeper understanding of current dementia course provision. This built on an earlier scoping survey<sup>13</sup> and aimed to explore the successes, adaptations and challenges in course delivery, for example in response to the COVID-19 pandemic. It gathered information on coproduction, course content, materials, outcome measures used, demographics, diversity, stakeholder engagement and the use of online platforms. The survey targeted two groups of staff: those working in (1) Recovery Colleges and (2) NHS memory and dementia services. Survey design prioritised clarity, accessibility and brevity, with piloting and feedback from PPIE and staff advisors. Response targets were set to ensure sufficient representation and targeted recruitment strategies were adjusted to address under-representation.

Quantitative data were analysed using descriptive statistics presented in tables and graphs. Qualitative data were analysed using Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) using basic content analysis, where open-ended responses were inductively coded by one researcher, discussed with the wider team and quantified by response frequency. Recovery Colleges provided demographic estimates (age, gender, ethnicity and socioeconomic indicators) of dementia course users, which were compared with regional demographics to assess equitable representation. Findings informed the selection of case study sites for the realist evaluation in WP2. Additionally, the survey functioned as a recruitment tool, inviting staff to express interest in joining the staff stakeholder advisory group.

### **Work package 1b: realist review methods**

Work package 1b comprised a five-step realist literature review to develop an initial programme theory (IPT) of a recovery-focused approach to adjusting to a dementia diagnosis and post-diagnostic support. Evidence was synthesised from diverse sources, including academic and grey literature, policy documents and related theories. The review protocol was registered with PROSPERO (CRD42021293687). Programme theory was refined with input from the two advisory groups.

Step 1 translated an existing Theory of Change map for Recovery College dementia courses into a realist IPT. This was achieved through team meetings, where causal explanations were generated to align with recovery principles and conceptual frameworks such as CHIME.<sup>23</sup>

Step 2 involved a rigorous search strategy covering peer-reviewed and grey literature, policy documents and materials from voluntary sector organisations. Targeted searches were conducted across multiple databases [PubMed, Cumulative Index to Nursing and Allied Health Literature, PsycInfo® (American Psychological Association, Washington, DC, USA)] and websites, with internet searches capturing blogs and vlogs from people living with dementia. Screening followed a two-stage process (title/abstract and full-text review), with a random subsample checked for consistency. Inclusion criteria focused on literature relating to people with dementia, their supporters and Recovery College courses within NHS settings.

In step 3, documents were appraised based on their relevance (whether sections of text contributed to programme theory development) and rigour (whether the data were sufficiently trustworthy). Step 4 involved

extracting descriptive and qualitative data, with relevant sections uploaded to NVivo software (QSR International, Warrington, UK) for qualitative analysis. A second researcher checked a random subsample for consistency.

The final step 5 involved data analysis and synthesis using a realist logic to develop Context–Mechanism–Outcome configurations, explaining how and why Recovery Colleges may produce intended or unintended outcomes. Key questions guided this process, examining the relationships between contexts, mechanisms and outcomes. Interpretive cross-case comparisons were used to explore the differences in implementation across settings, employing techniques such as juxtaposing, reconciling, adjudicating and consolidating data to refine the IPT.

### **Work package 1c: stakeholder advisory group discussion methods**

Two 2-hour discussion meetings were scheduled to review the IPT and discuss emerging findings from WP1b. The meetings were held online [via Zoom (Zoom Video Communications, San Jose, CA, USA) or Microsoft Teams], and to maximise attendance, both groups were invited to both meetings, scheduled on different days and times (morning/afternoon) within the same week. The meetings were facilitated by study team members experienced in working with people with dementia and NHS services. The IPT was presented in an accessible way, using vignettes, and group members were invited to share their thoughts. Discussions took place in smaller virtual rooms of up to six people, with separate groups for staff and people with dementia and family supporters to ensure comfort. Facilitators took notes, and discussions were recorded to assess whether the findings aligned with the IPT and to identify any necessary refinements.

### **Work package 2: realist evaluation methods**

Work package 2 was a realist evaluation that examined multiple sources of data from five embedded case studies. Data from this WP were synthesised alongside survey findings from WP1 to test (confirm, refine or refute) the IPT. Each case study site was an NHS mental health organisation offering a Recovery College course on living with dementia post diagnosis. Data collection involved a combination of focused ethnography, realist interviews and documentary analysis. Observations of Recovery College dementia courses were conducted with researchers embedded as participants to minimise disruption while gathering insights into course delivery. Interviews explored experiences of coproduction and attendance. The questions centred around how participant found out

about the course, did they have any concerns beforehand and what were the positives and negative outcomes from attending the course. There was an additional survey and interview held for individuals from ethnic and cultural minority backgrounds to examine barriers to engagement. Documentary evidence, such as coproduction meeting notes and course materials, provided further context on course implementation.

Data were analysed iteratively using a realist logic, incorporating deductive, inductive and retroductive coding to explore the relationships between contexts, mechanisms and outcomes. Cross-case comparisons were conducted to identify factors influencing successful course implementation and to refine the programme theory. We also considered formal (or substantive) theories underpinning explanations for how mechanisms worked in specific contexts to lead to outcomes. The conceptual CHIME framework<sup>23</sup> and theories underpinning a person-centred approach to dementia<sup>34</sup> were mapped using an online collaborative tool.<sup>35</sup> Research team meetings identified further conceptual models that explained the value of collaborative and interactive processes in Recovery College dementia courses (see [Appendix 1](#), [Figure 2](#)). These included theories of hope<sup>36</sup> and how people with dementia create meaning in everyday social interactions.<sup>37</sup> Full details of methods are described in the 'Protocol for a realist evaluation of Recovery College dementia courses: understanding coproduction through ethnography' are published in the journal *BMJ Open*.<sup>15</sup>

All consent procedures carried out during the study were completed in a way that takes into consideration the needs of people with dementia, including anyone who may lack capacity and adhere to the Mental Capacity Act (2005) and its accompanying Code of Practice.

Initially, researchers liaised with case site leads to arranged informal meetings with the coproduction group(s). During these meetings, they gave information about the study, answer any questions and begin to discuss and plan to join DiSCOVERY College Dementia Course meetings as ethnographic observers of the coproduction process.

Attendees enrolling on the Recovery College dementia course at each site were advised of the planned research. All potential participants were given an information sheet to explain the study and their role within this. The information sheet was also verbally explained, with the chance for discussion and for people to ask any questions they may have before the course commenced. The participant information sheets were reviewed by the PPIE advisory group to improve accessibility.

For people with dementia, the initial discussion was used by the researcher (who is trained in this process) to assess whether the potential participant had the capacity to decide whether they would like to participate in the study or not. This decision was made based on whether the person was able to understand, retain and use the provided information to make a decision. If the person was not deemed to have capacity but showed no signs of unwillingness to take part, the advice of a personal consultee would be sought.

As part of the consent process, course attendees were offered the opportunity to participate in an interview following the Recovery College dementia course. All interviews were scheduled at the participants' earliest convenience, with most of these taking place within a week of the course taking place. These were conducted either face to face or online. For WP5, interviews took place within 2 weeks of the course and were conducted exclusively online.

### **Work package 3: scoping review methods**

The output of this stage was a selection of relevant outcome measures, consistent with the programme theory, to accompany the materials and resources in WP4. A range of outcome measures was reviewed and selected using peer-reviewed literature. Relevant positive psychology outcome measures (PPOMs) available and validated for use in relation to dementia were identified, along with papers from the realist review in WP1. Outcome domains from the programme theory were presented and discussed with the two stakeholder advisory groups to gather feedback on the selected outcome measures for evaluating the impact of Recovery College dementia courses.

### **Work package 4: guidance resources methods**

The output of this WP was a set of coproduced guidance resources and recommendations to, in turn, support the coproduction of Recovery College dementia courses within NHS memory services. Working with the Partners in Research and staff advisors, guidance was codeveloped on how to effectively consider, set up and run a Recovery College dementia course. Three rounds of workshops were held to coproduce these resources.

### **Work package 5: equality, diversity and inclusion methods**

Work package 5 was developed mid-study using additional funding and embedded throughout all WPs. It involved a multimethods approach to data

collection, specifically focusing on the experiences of Recovery College dementia courses and wider beliefs of post-diagnostic support for dementia, from the perspectives of people with dementia, their family supporters and healthcare staff from diverse ethnic and cultural backgrounds.

We conducted additional qualitative interviews with those from diverse ethnic and cultural backgrounds who had either coproduced or attended Recovery College dementia courses from each of the four case sites and who agreed to an interview. Three interview topic guides, one for family supporters, one for people with dementia and one for staff, were cocreated through discussions with representatives from diverse ethnic and cultural backgrounds and explored through a realist lens: (1) experiences of coproducing or attending Recovery College dementia courses in terms of inclusion; (2) supporting inclusion and diversity with co-facilitators and attendees (3); how courses met or did not meet cultural needs; (4) how future courses could meet wider ethnic and cultural needs of attendees; and (5) facilitators and barriers to attending courses. Due to the limitations in diversity of Recovery College attendees, only two of the interview topic guides were used, as no person with dementia from an ethnic minority background was identified for interview.

In order to increase the diversity of voice and experiences related to ethnic and cultural minority groups, an accompanying online survey was developed and distributed to people involved in the dementia care pathways and services in which Recovery Colleges were active, with different survey branching and questions developed for people with dementia, family supporters and healthcare staff. The survey focused on views of current post-diagnostic dementia support for people from diverse ethnic and cultural backgrounds, the perceived role of Recovery College dementia courses for people from diverse ethnic and cultural backgrounds and identification of course adaptations needed to ensure inclusion. Interviews were conducted using MS Teams and were recorded with participant consent. Following a 2-month survey collection period, the surveys were closed, and participant NHS organisations were updated on their progress.

Data were collated across the interview and survey data and were analysed using content analysis.<sup>38</sup> Initial themes were generated reflecting the wider social and system experiences of living and working with dementia in memory and dementia services. Initial themes were discussed with the wider DiSCOVERY team, which includes

people from diverse cultural and ethnic backgrounds, who commented on the authenticity and interpretation of findings from lived and professional perspectives. Context (C)–Mechanism (M)–Outcome (O)–Configurations (C) (CMOCs) and underlying themes from the data were incorporated into the programme theory through team discussions, including with staff advisors and the Partners in Research group. Considerations for inclusive course development were embedded into the WP4 guidance resource outputs.

## Results

### *Work package 1a: staff survey results*

A total of 261 responses were collected, including 51 from Recovery College staff and 210 from memory and dementia services across the UK, with the highest responses from London (73, 27.97%), East of England (55, 21.07%) and Yorkshire and the Humber (46, 17.62%). Twelve Recovery College dementia courses were reported nationwide. In terms of reported demographics, most attendees were described as aged 56–65 years (35.1%) or 66–75 years (31.9%), with women making up 66% and men 33.4%. Ethnic representation included 79.3% White British and 14.7% Asian/Asian British. Three key themes were identified from basic content analysis of qualitative data: post-diagnostic support, recovery in the context of dementia, and challenges and innovations. Full details of methods and findings from ‘Building an initial understanding of UK Recovery College dementia courses: A national survey of Recovery College and memory services staff’ are published in the *Journal Working with Older People*.<sup>16</sup>

### *Work package 1b: realist review results*

A review of 35 papers, blog posts and discussions with stakeholders (9 staff and 10 people with lived experience) developed IPT of 24 CMOCs, explaining interconnected factors related to coproduction and co-facilitation of Recovery College dementia courses. The IPT addressed several key areas:

Review CMOCs 1 and 2 explained the decision to run a course. Services consider the Recovery College model as appropriate for people with dementia when they recognise the benefits for mental health conditions. However, pressure from financial instability and staffing constraints limit resources for coproducing dementia courses.

Review CMOCs 3–7 addressed identifying staff member(s) and people with lived experience of dementia to coproduce the course. Staff who value principles of personal recovery

are likely to initiate coproduction of courses and identify people with dementia who may benefit from becoming a peer tutor, through their clinical relationships. Peer tutors, whether they be people with dementia or family supporters, gain a sense of purpose and confidence by being supported to coproduce, codeliver and share their lived experience on courses.

Review CMOCs 8–12 detailed the process of coproduction of courses. Staff and peer tutors coproducing courses together can break traditional ‘professional/client’ boundaries, cultivating an honest, supportive and respectful environment, important for shaping a dementia course. Time, adaptable clinical skills and mutual respect for lived experience from staff are also important for coproduction.

Review CMOCs 13–17 described receiving information about the course and signposting. The experience of receiving a diagnosis of dementia is overwhelming and devastating, therefore providing course information needs to be at appropriate times. Additionally, course content needs to address the benefits and risks of attending the course to enable people to make informed decisions about attending. Trusted people, healthcare staff and local social care sector organisations all play a key role in raising awareness and encouraging people to attend.

Review CMOCs 18–19 outlined the decision to attend or not attend the course, which can be influenced by misinterpreting or disagreeing with the concept of personal recovery in dementia. Courses designed using suitable formats, length and venue are more likely to appeal to prospective attendees.

Review CMOCs 20–23 described skilled co-facilitators building a safe environment to enable shared learning. Importantly, the IPT suggests that seeing peer tutors with dementia living positively may help attendees with dementia to recover a sense of control over their lives. A co-facilitated course can also positively shape the clinical practice by staff attendees understanding what is meant by living positively with dementia.

Finally, review CMOC 24 proposes that course evaluations can influence the decision to rerun Recovery College dementia courses. Evaluations can refine course content and increase engagement with individuals who may benefit from attending. Details of methods and findings from ‘Operationalising the Recovery College model with people living with dementia: a realist review’ are published in the journal *Ageing and Mental Health*.<sup>17</sup>

### **Work package 2: realist evaluation results**

The realist evaluation expanded the realist review by empirically confirming, refining or refuting IPTs. Five dementia courses were observed in four NHS mental health organisations. These organisations covered urban and rural populations. The courses they delivered were different in delivery method and length of delivery. 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. Of the individuals observed ( $n = 104$ ), a mix of 45 staff and peer tutors, course attendees and Recovery College and dementia service leads were interviewed across the 5 case studies (see [Table 2](#) for sample and role characteristics).

Findings from ethnographic observations and interviews with tutors and attendees identified 4 primary, overarching CMOCs related to course staging, supported by 26 granular CMOCs across 4 steps: setting up, advertising, delivering and evaluating Recovery College dementia courses, summarised here.

### **Setting up courses**

#### **Overarching Context–Mechanism–Outcome–Configuration**

If there is an organisational and/or a personal ethos of coproduction and recovery in relation to post-diagnosis dementia support (C), then this encourages staff, and people with lived experience, to coproduce dementia courses (O) because they believe it fits with service and/or personal values and aims (M).

Evaluation CMOCs 1–11 expanded the review IPTs by providing details on staff decisions on setting up a course and coproduction partners. Staff were intrinsically motivated to set up courses, recognising the relevance of coproduction and personal recovery for dementia support. External motivators for staff included hearing about course benefits, being offered institutional support from Recovery Colleges and the need to bridge post-diagnostic dementia support gaps. Staff identified potential coproducers based on experience and qualities, with peer tutors participating in order to help others navigate living with dementia. Succession planning was crucial to ensure tutors’ evolving needs were supported and to maintain course stability. Additional support is also important for new peer tutors who join an established course without prior involvement in its setup to integrate their experiences and skills within the existing structure.

TABLE 2 Work package 2 sample and role characteristics

	CS1 in person		CS2 online		CS2.2 in person		CS3 in person		CS4 online	
	Observed	Interviewed	Observed	Interviewed	Observed	Interviewed	Observed	Interviewed	Observed	Interviewed
Staff tutor	1	1	1	1	1	-	2	2	2	2
Person dementia peer tutor	1	1	1	1	1	(1) Same person as CS2	2	1	-	-
Family supporter peer tutor	1	1	-	-	-	-	2	2	1	1
Staff attendee	1	1	8	1	18	2	1	-	1	-
Person dementia attendee	4	2	4	-	5	4	4	2	2	-
Family supporter attendee	5	2	7	2	9	6	4	2	8	3
Support staff	3	1	1	-	1	-	-	-	1	-
Service lead/ manager	-	1	-	-	-	-	1	1	-	1
	16	10	22	5	35	13	16	10	15	7

CS, College setting.

## Advertising courses

### **Overarching Context–Mechanism–Outcome–Configuration**

If a range of partnership organisations and local professionals know about a Recovery College dementia course and are willing to discuss its potential benefits with people with dementia they work with (C), then it is likely that people might be more willing to attend the course (O) as they become aware of possible value to them (M).

Evaluation CMOCs 12–16 refined the realist review IPTs on course signposting and attendance decisions. The evaluation suggested that people were more likely to attend when informed by trusted sources, informed at an appropriate time and when the course reflected their needs. Representation of different needs was important by including dementia experiences from individuals with diverse ethnic and cultural perspectives in coproduction. Clear course information was beneficial but could be overwhelming if given at the point of diagnosis; providing it later through trusted networks supported better decision-making about whether to attend or not.

## Delivering courses

### **Overarching Context–Mechanism–Outcome–Configuration**

Where the format and delivery method of a Recovery College dementia course creates a space for social connections and sharing experiences, along with supporting accessibility and support needs of those attending (C), the course will more likely appeal to the intended audience (O) as people think they will be able to cope with attending (M).

Evaluation CMOCs 18–24 confirmed the IPTs from the realist review which suggested that dyads attending needed to feel capable of attending and required a safe space to openly discuss experiences of living with dementia. The evaluation highlighted the importance of the Recovery College model, which emphasises embedding principles of personal recovery, adult learning and sharing of experiences to cultivate hopefulness in living positively with dementia. Course content focused on medical causes of dementia was less relevant to some, especially to those with rarer dementias. Course outcomes were influenced by the delivery method, with social connections best developed across several sessions by allowing attendees time to adjust and feel settled. Delivering online courses benefited family supporters, while in-person sessions in community-based venues encouraged more engagement from people with dementia. Online courses presented

challenges, as attendees with cameras off became an ‘invisible presence’ affecting the sense of emotional safety.

## Evaluating courses

### **Overarching Context–Mechanism–Outcome–Configuration**

If Recovery College dementia courses have processes to monitor quality and outcomes (C), then they can provide evidence of their benefit as a form of post-diagnostic support (M), enabling others to see their place in post-diagnostic provision (O).

The review highlighted that course evaluation could inform change and improve dementia courses; however, there was limited evidence found for this in the realist evaluation.

Evaluation CMOCs 25–26 described that while course evaluation was valued by the Recovery College, systematic evaluations or measures of meaningful outcomes pertinent to dementia were limited. Two main evaluation methods existed: postcourse evaluations, which were not frequently completed, and Recovery College staff observations every 6–12 months. This monitoring helped to maintain recovery-focused principles and improve courses. However, evaluating dementia courses remained challenging due to the fluctuating emotions and cognition of people with dementia attendees, often leading to discrepancies between their accounts and those of family supporters. ‘In the moment’ evaluation was identified as necessary to appropriately capture experiential benefits and the impact of the course due to the risk of gatekeeping access to dementia courses.

Additional analysis examined data to specify the activities of peer tutors and the mechanisms which shaped outcomes for people with dementia. Four primary, overarching CMOCs were supported by 20 granular CMOCs that refine IPTs, grouped under 3 key themes: (1) empowering and enabling non-stigmatised identities; (2) managing uncertainty for positive reframing and (3) connecting together enabling hope, presented here:

### **Theme 1: empowering and enabling non-stigmatised identities**

#### **Overarching Context–Mechanism–Outcome–Configuration**

When people with dementia who are adjusting to their diagnosis attend a Recovery College Course that provides them with emotional and peer support (C), this 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).

Evaluation CMOCs 1–5 described how Recovery College dementia courses helped people with dementia to accept their diagnosis by providing a supportive environment where they could build confidence and live positively. Learning about the types of dementia reinforced that it is beyond their control, reduced self-blame and assimilated dementia into their identity. Peer tutors sharing their inspiring experiences of managing symptoms positively empowered attendees with dementia to gain a sense of control over their lives. When people with dementia felt ready to attend after their diagnosis and courses created a space to validate experiences, it enabled people to process their diagnosis through peer support. Additionally, reinforcing the importance of maintaining social connections with people and valued activities helped attendees regain their identity, meaning and sense of purpose.

### **Theme 2: managing uncertainty for positive reframing**

#### **Overarching Context–Mechanism–Outcome–Configuration**

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 with dementia will feel able to remain in the Recovery College session (O).

Evaluation CMOCs 6–8 outlined how skilled co-facilitation by tutors helped attendees navigate the emotional impact of dementia by ensuring psychological safety and emotional support. Tutors who sensitively diffused distress created a space where people with dementia shared their personal experiences and felt supported. Balanced discussions helped prevent dominant voices from overshadowing others, ensuring that all attendees feel heard and valued. However, limited session time can sometimes restrict opportunities for meaningful contributions and emotional engagement.

### **Theme 3: connecting together enabling hope**

#### **Overarching Context–Mechanism–Outcome–Configuration**

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).

Evaluation CMOCs 9–20 suggest how recovery-focused dementia courses enabled people with dementia to gain new perspectives in their relationships and diagnosis by cultivating social connectedness. Extra support and time to settle in reduced social nervousness, while non-dementia-related warm-up activities created a relaxed and inclusive atmosphere. Informal interactions, such as conversations during breaks, provided further opportunities to connect and build relationships, leading to open discussions during wider sessions and small groups. For some who had difficulty in actively engaging through conversation still benefited through observation and listening to others, with peer tutors empowering these individuals to contribute. Peer tutors modelling a positive life post diagnosis helped individuals to believe that there is hope when living with dementia, connected by shared lived experience. Hearing others' lived experiences fosters a sense of solidarity and belonging, with honesty from peer tutors increasing connectedness with attendees. Practical strategies shared by peer tutors empowered individuals to navigate their own experiences. When course materials did not reflect a range of different lived experiences and lacked cultural representation, some attendees felt that they did not benefit from the content. Often, this was because they did not see their personal experiences reflected in the learning materials.

Details of methods and findings from the second paper: 'Role of peer tutors with dementia in Recovery College dementia courses: an ethnographic account' has been published in *Gerontologist*.<sup>19</sup>

#### **Additional results**

Here, we present additional findings from the data not published elsewhere, but which were important in informing the values underpinning the coproduction of guidance resources in WP4.

#### **The role of family supporters within Recovery College dementia courses**

Firstly, we highlight the important role of family supporters during and following dementia courses in supporting a person with dementia's process of personal recovery. For some people with dementia, the journey to learning to live with dementia was a shared experience that required family members to work together with the person. Some family supporters became advocates after their relative's

difficult diagnosis experiences, intrinsically motivated to help others navigate their dementia journey with positivity by becoming peer tutors. A family supporter in the Partners in Research group recalled feeling isolated at the time of diagnosis, *'Our experience has been you lose a year of your life collapsing your life inside itself, shutting down, not wanting to talk to anybody, frightened to talk to people'*. This emphasises the negative impact of a poor diagnosis experience for both the family supporter and person with dementia. The data suggest that Recovery College dementia courses are important for cultivating hope after diagnosis not only for people with dementia but also for family supporters. Along with people with dementia, family supporter peer tutors not only empowered others by sharing their lived experiences and coping strategies but also derived a sense of purpose from the role and learned new strategies from attendees, benefiting mutually. A family supporter peer tutor said, *'I really like that I can hopefully help people to live well with dementia and help their carers to care for them in the best way'*.

The shared experience of dementia between family supporters and people with dementia, required collaboration, resilience and coping. The course provided a structured environment for supporters to reframe their roles as enablers to empower their relatives to increase control and autonomy by developing positive coping strategies and adaptations. This could increase hopefulness in a process of personal recovery together, with the family supporter positively reinforcing and holding a person's identity following a dementia diagnosis. A family supporter peer tutor said: *'There is a next. It's not, "Oh my god we've got a dementia diagnosis, that's it". There is a next, there is something next. Next can still be exciting, it can still be enjoyable, it can still be a challenge and you can do it'*. In addition to practical guidance, the peer supportive environment of the dementia courses was essential in reducing isolation, validating emotional experiences and reassuring family supporters that they are helping their relative in the best way possible. Supporters reported that sharing experiences with other attendees helped them feel less alone, with one family supporter attendee remarking, *'At least somebody had an understanding of what it's like to care for someone'*. Despite these benefits, some challenges were identified. A mixed audience of people with dementia and family supporters within sessions, at times, impeded open dialogue on sensitive issues, and the use of online formats could lead to family supporters dominating discussions. Furthermore, concerns were raised by family supporter attendees about limited cultural relevance of course content,

diversity of caregiving roles and the types of dementia being represented, highlighting areas for further course planning refinement.

### Creating an inclusive learning environment and adjusting for dementia

Secondly, all Recovery College courses promote an expectation that content will be person-centred, that materials will draw on social models of health and common 'professional/client' power imbalances will be equalised through the process of coproduction and skilled course co-facilitation. Here, we draw out a further component not reported in the second paper due to word limits<sup>39</sup> but which provides further context within which people with dementia can feel included and also those aspects which might inadvertently generate outcomes of 'malignant positioning'. This refers to ways in which people with dementia can be treated that make people feel inferior, powerless or dependent, often unintentionally, through interactions and social environments that undermine personhood, dignity and well-being.<sup>34,37</sup> We examine this through the authenticity of the peer tutor in reactions to material, which underpinned the coproduction of the practical guidance in WP4.

### Authenticity of peer tutor in reactions to material

We did observe course content which potentially positioned people with dementia within a 'malignant psychology', being people without capacity and presenting with challenging symptoms. The use of videos was a powerful medium that worked best when there was time for the group to discuss how they felt about it and what they had learned. When a video of a family member talking about the challenges of caring for a person with dementia was shown, we observed people looking down at the table and there was no space for discussing how people felt after that as the activity moved straight on to what family supporters can do to look after themselves. This was in a room with people with dementia who had attended with family supporters and those who had attended alone. We suggest this may negate messages of hope of living positively with dementia. By contrast, this extract from ethnographic observations illustrates positive facilitation skills even when the content of the activity may shine a spotlight on the some of the difficulties that dementia can bring to individuals:

**Observation extract learning material – watching a 10 minute video made by [name of peer tutor with dementia not present]. Introduced by staff tutor and acknowledged that this person and their wife had co-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-staff tutor then led discussions by inviting reactions to the video, recording them on a flipchart. An attendee with dementia smiles and shares thoughts about finding purpose which the staff tutor builds on. The peer tutor with dementia is very emotional after the video despite having seen it several times in previous courses. She discusses her reaction with the group which the staff tutors help to defuse. They acknowledge the difficulties. The peer tutor with dementia emphasises 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, with the discussion including another attendee with dementia who didn't always overtly participate.*

This fieldnote illustrates how the peer tutor with dementia was prepared to share emotion, which may enable attendees to be open about their emotional reactions. This extract also demonstrates the need for preparation for an activity and time for people to discuss afterwards. In single sessions lasting no more than 2.5 hours, we noted that there was more limited time for discussion and conversations, and comments were sometimes 'shut off' in order to cover all of the planned course content.

### **Work package 3: scoping review results**

Twenty nine thousand nine hundred and nineteen citations were retrieved from six academic databases and were screened at abstract and title levels. Eighty-seven measures for people with dementia and 65 measures for family supporters were full-text screened. Key domains of outcomes identified through stakeholder discussions included hope, coping, empowerment, resilience and self-efficacy. A total of 14 measures were eligible for the review.

Psychometric properties were assessed using Terwee's criteria, which include construct validity, reproducibility, reliability, responsiveness, floor/ceiling effects and interpretability.<sup>40</sup> Each measure was appraised using

a scoring system (0–18), categorised as poor (0–4), moderate (5–9), good (10–14) and very good (15–18). Most measures scored in the moderate-to-poor range, and none were rated as very good. This highlights the need for further development and psychometric validation of outcome measures of personal recovery pertinent to dementia outcomes. Four measures were rated as good and are tentatively suggested for further adaptation and validation in Recovery College dementia courses. These are explained below.

### **Domain: hope and resilience**

The 16-item PPOM consists of two subscales assessing hope and resilience in people with dementia,<sup>39</sup> while the 14-item PPOM-C is designed for caregivers.<sup>41</sup> The PPOM scored 11/18, and PPOM-C scored 10/18, demonstrating adequate content validity, moderate interpretability for the PPOM and moderate reproducibility by both.

### **Domain: empowerment**

The 26-item Engagement and Independence in Dementia Questionnaire (EID-Q) has 5 subscales evaluating Activities of Daily Living, Decision-Making, Activity Engagement, Support and Reciprocity for people living with dementia,<sup>42</sup> with 11/18 in quality rating, The EID-Q indicated good internal consistency, reproducibility and content validity, utilising strong stakeholder engagement during item selection.

### **Domain: caregiver self-efficacy**

The 8-item Caregiver Self-Efficacy Scale (CSES-8), which assesses self-efficacy in caregiving tasks such as stress management, self-care, finding resources and coping with new situations,<sup>43</sup> rated 10/18 with moderate responsiveness and interpretability. Content validity is poor and reproducibility is methodologically inadequate.

Several other measures were rated as poor to moderate, requiring further psychometric refinement, with full details of 'A scoping review of outcome measures for people living with dementia and family supporters to evaluate Recovery College dementia courses' published in the journal *Frontiers Psychiatry*.<sup>18</sup>

### **Work package 4: guidance resource results**

The coproduction process in WP4 led to the development of five guidance documents sharing learnings from the DiSCOVERY study through practical guides and suggestions for developing, implementing, evaluating and sustaining Recovery College dementia courses. The guidance is deep-seated in lived and learned experience of dementia through strong collaborative work with our stakeholder groups. The guides outline important

considerations: the coproduction process for staff, for people with dementia, working together with family supporters, logistics for setting up and codelivery, and sustainability of dementia courses.

*Guide 1: Considering a Recovery College Course about Dementia* – this introduces the purpose and benefits of a Recovery College dementia course and coproduction when considering post-diagnostic support. The guide emphasises the concept of personal recovery and the role of peer tutors with dementia, highlighting the importance of hope, social connection and shared learning for people adjusting to a dementia diagnosis.

*Guide 2: Identifying Tutors and coProducing Content* – this provides practical strategies for selecting and supporting peer tutors with lived experience of dementia as co-facilitators of the course. The guide outlines the best practices for coproduction, including developing content collaboratively to reflect lived experiences, and ensuring accessibility in meetings.

*Guide 3: Being a Peer Tutor* – this was written by people with dementia for people with dementia by the Partners in Research group, offering guidance on what to expect from the role, and strategies for managing personal health and well-being while supporting others.

*Guide 4: Setting Up, Advertising, and Running a Course* – this guide provides recommendations on how to establish a Recovery College dementia course. This includes choosing a suitable venue and course format, structuring course sessions, advertising to potential attendees and ensuring that course materials are accessible and inclusive of different experiences and perspectives.

*Guide 5: Evaluating and Sustaining a Course* – this details methods for measuring the impact and long-term sustainability of the course, including practical recommendations on collecting feedback and outcome measure data to demonstrate effectiveness to commissioners and service leaders. There is also guidance on sustainability plans such as building relationships with local Recovery Colleges and implementing peer mentorship plans to support future tutors.

### Additional resources

To compliment the written guides, additional resources were developed to enhance engagement and accessibility. A dedicated web page ([www.nsfh.nhs.uk/discovery-study](http://www.nsfh.nhs.uk/discovery-study)), provides information about the DiSCOVERY study and download links to the guidance resources, either

single guides for use as information sheets, for example for healthcare staff to give to potential peer tutors with dementia, or the whole pack. A short video was produced to introduce the meaning of personal recovery in dementia and provide an overview of how to use the resources available on the DiSCOVERY study website. Additionally, the Partners in Research group recorded a podcast, discussing their lived experiences and dementia courses, reflecting on personal recovery and the importance of peer support and hope. The podcast is available at [www.dementiadiaries.org](http://www.dementiadiaries.org)

### Work package 5: equality, diversity and inclusion results

Due to the small number of people from cultural and ethnic minority backgrounds attending Recovery College dementia courses in the case sites, only two qualitative interviews were conducted with attendees and co-facilitators of Recovery College dementia courses from case study sites, with one family supporter and one member of healthcare staff from ethnically diverse backgrounds.

To increase the diversity of voices and views of Recovery College dementia courses, we also developed online surveys for healthcare professionals, family carers and people with dementia from cultural and ethnic minority groups, who had accessed memory services within case sites and from sites who had expressed an interest in participating. Out of 54 respondents, 43% ( $n = 23$ ) were from an ethnic minority background. Twenty-one identified themselves as being from defined ethnic and cultural minority background, with 2 further people stating that they were from an ethnic minority background but declined to specify. All White British respondents stated that they worked with people with dementia and carers from ethnic minority backgrounds. See [Table 3](#) for a self-described ethnic demographic summary.

The 54 respondents reflected the views of 35 healthcare professionals, 14 carers and 5 people with dementia.

Three overarching themes were generated from the combined interview ( $n = 2$ ) and survey data ( $n = 54$ ), reflecting the considerations and perspectives of ethnic and cultural inclusion in Recovery College dementia courses, presented below.

### Theme 1: diverse cultural beliefs and awareness of dementia and dementia care

This theme involved perspectives as to social and cultural belief factors that influenced whether people from diverse ethnic and cultural backgrounds were unwilling, or unable,

**TABLE 3** Work package 5 survey: self-described ethnic demographic summary

Identified ethnic background	n	%
Asian/Asian British	8	14.8
Black African/Caribbean/British	5	9.3
Arab	1	1.85
Mixed-multiethnicity	2	3.7
Gypsy, Roma, and Traveller	1	1.85
Non-specified minority	2	3.7
White other (i.e. E. Europe)	4	7.4
White British	31	57.4

to attend Recovery College dementia courses. The impacts of these beliefs were associated with late diagnosis of dementia, unwillingness to speak with strangers over symptoms and conflicts created in families over traditional cultural expectations of the family supporter role. This theme was raised in 61% of responses.

Subthemes:

- cultural stigma of dementia condition and services
- diverse cultural beliefs of dementia causes
- expectation of family as primary support
- lack of awareness of system support options.

Illustrative quotes reflecting individuals' views:

*I think more seems to be done around normalising dementia as an issue in the wider community, GPs possibly need to be more proactive in promoting recovery colleges.*

*Healthcare staff member*

*I think that the biggest problem I see is that this particular group (Ethnic minority groups) can sometimes mistrust services, keep things within the family, with links to shame and gossip.*

*Healthcare staff member*

*(Seeking dementia care) is not their culture, it is a family thing.*

*Healthcare staff*

*And they're like, quite close family. So, there is resentment which actually happens sometimes within the families ... the culture is such that the*

*son takes majority of the rules and responsibility for elderly parents.*

*Healthcare staff member*

*The people I see have a learned helplessness because mom or dad can't speak English. So there is no remit in accessing the support services like Carers or (Local charity supporters) or things like that, and might as well just do it within the family.*

*Healthcare staff member*

## Theme 2: language barriers due to system limits

This theme, which was reflected in 53% of responses and primarily from healthcare staff respondents, involved the systemic challenges in supporting language and communication needs in diverse course attendees. The impacts of these challenges were identified as creating barriers for the promotion of Recovery College dementia courses to people who did not speak English, challenges in multilingual courses and hesitancy to attend from community members concerned about language barriers, which resulted in lower engagement and need for a language provision.

Subthemes:

- poor quality of interpreter services and lack of dementia awareness
- lack of face-to-face interpreter provision for courses.

Illustrative quotes reflecting individuals' views:

*Language barriers can lead to a lesser ability to adequately explain the benefits of participating.*

*Healthcare staff member*

*Language/no verbal communication may vary, and cultural nuances (understanding the variations in norms and values such as religious beliefs and attitudes toward professionals of same gender and so on).*

*Healthcare staff member*

*There aren't sufficient numbers to provide (a separate language-specific course) for a three monthly course.*

*Healthcare staff member*

## Theme 3: wider system and service barriers to attending Recovery College dementia courses

This theme, involving 30% of responses, reflected on the wider service and pathway barriers to dementia diagnosis, lack of culturally specific group options, and upstream

capacity problems in dementia clinical pathways which prevented people from being referred to, or participating, in Recovery College dementia courses. Other impacts of these barriers identified included professional knowledge gaps of culturally appropriate dementia care including food, faith and location preferences, poorer confidence in diagnosing dementia and services not offering post-diagnostic support.

Subthemes:

- culturally inappropriate dementia screening tools
- few culturally inclusive and specific group options
- bottlenecks in upstream services preventing referrals
- workforce limitations to support inclusion.

Illustrative quotes reflecting individuals' views:

*An interpreter once told me that older people from Iran are not always aware of today's date, as it's not something that's commonly known in their culture. But they do get a lower score on their cognitive test.*

*Healthcare staff member*

*Lately, her interests are more focused towards her religion and she spends a fair bit of time on that. Ideally, if she could practice this in a group setting, it would help.*

*Family supporter*

*Important for my relative to 'tap in' to West Indian culture, particularly by staying in touch with family and friends. Maintaining/establishing social connections with the West Indian community through multicultural groups, events and so on.*

*Family supporter*

Collectively, the findings from this additional work led to the development of equality, diversity and inclusion (EDI) CMOCs, which related to both Recovery College dementia courses and how to best engage with diverse communities:

EDI CMOC1: Health or social care staff raising awareness of dementia in diverse ethnic and cultural communities through education and culturally inclusive screening tools (C) will normalise speaking about the condition and will help to reduce cultural stigma of dementia (O) because it increases family acceptance and early access to support on offer (M).

EDI CMOC2: Increasing active signposting, by trusted sources, of Recovery College dementia courses to people from diverse ethnic and cultural backgrounds during memory and dementia service and

GP appointments (C) will likely increase engagement in courses (O) because of increased awareness and receptivity (M).

EDI CMOC3: Promotion of Recovery College dementia courses by primary healthcare staff as a whole family opportunity to help families from diverse backgrounds living with a person with dementia (C) offer greater chances of engagement with Recovery College dementia courses (O) because they can understand the potential benefits (M).

EDI CMOC4: Healthcare staff in primary care or memory services promoting social connection and informal culturally inclusive social opportunities as part of Recovery College dementia courses (C) will help to increase interest in these courses (O) because it is seen as a culturally safe space in which to share memories and practices (M).

EDI CMOC5: Including culturally diverse case stories, references and activities in Recovery College dementia courses (C) will help to support discussion, make meaning of and increase acceptance of dementia in people from diverse ethnic and cultural backgrounds (O) because these are more likely to resonate with participants and connect them to shared experiences (M).

EDI CMOC6: Courses co-facilitated by people from the same ethnic and cultural backgrounds as families (C) will be more likely support feelings of belonging, shared identity and empathy (O) because participants are more likely to personally identify with the facilitators (M).

The findings from WP5 revealed the continuing perceptions of how upstream blocks in dementia care systems and services can prevent people from diverse ethnic and cultural backgrounds being offered opportunities to be involved with Recovery College dementia courses as either peer tutors or attendees. In addition, cultural expectations around the role of family members as principal supporters and deep mistrust in communities can act as barriers to people wishing to engage. Recovery College dementia courses should consider how to be culturally inclusive where appropriate for their local populations, including language support, culturally inclusive case studies and culture-specific social opportunities.

### **Advisory groups engagement in analysing data across all work packages**

By reflecting on their lived and learned experiences of dementia, group members provided valuable insights to help develop IPTs in the realist review, refine realist evaluation CMOCs with a nuanced perspective, identify important domains of outcome measures and inform and coproduce guidance resources.

### Research papers

The details of methods and findings summarised in [Methods](#) and [Results](#) are reported in eight publications referenced in [Table 1](#), together with preparatory work for the funding application from 2019 to 2022. A full list of outputs and dissemination are summarised in [Appendix 2](#), [Table 4](#).

### Future publications

The following publications are in preparation and are not submitted at this time. They are listed for completeness but have not been cited within the main report:

- Co-produced, peer supported post-diagnostic dementia support: a realist evaluation of Recovery College courses.
- People with lived experience of dementia as 'Partners in Research' in the DISCOVERY project.

## Discussion

This programme of work draws together data from diverse sources, but the golden thread is the importance of coproduction and codelivery with people with dementia for ensuring the relevance and resonance of this form of post diagnostic support. Recommendations and conclusions need to be considered within the context that data are predominantly drawn for tutors and attendees of White heritage and it is known that people from minority ethnic groups can experience barriers to access dementia services.

The initial programme theories were developed through an online survey and a realist review. The survey of staff working in Recovery Colleges and memory services found bespoke dementia courses based around the 'living well' agenda,<sup>33</sup> covering topics such as adjustment, managing symptoms and how to live positively and reported positive outcomes. However, there was limited representation from different ethnic groups as the survey found that 12 UK Recovery College dementia courses were mostly attended by women, people aged 56–75 years and those of White British ethnicity. Notably, attendees from Black ethnic groups were under-represented despite reports of a higher incidence of dementia.<sup>44</sup> We aimed to increase the ethnic and cultural diversity of voices in this project through the conduct of a second survey aimed at understanding views and experiences of ethnic minority family carers, people with dementia and healthcare professionals, and this work is presented within this synopsis. However, the under-representation suggests potential barriers to

access and highlights the need for further investigation, particularly as the number of people with dementia from diverse ethnic and cultural backgrounds is expected to increase.<sup>20</sup> The survey revealed divisiveness over the term 'recovery' in relation to dementia, with some seeing it as empowering and others as potentially misleading, offering false hope of a cure. This reiterates the importance of careful terminology in dementia care.<sup>10</sup>

Survey responses indicated that the importance of the coproduction aspect – where people with dementia actively participated in co-designing and codelivering the courses – was identified as an important strength, enhancing the relevance of dementia courses. These findings resonated with an allied study which found that a person with dementia, their family supporter and healthcare staff involved in coproducing a Recovery College course valued coproduction and peer-to-peer learning, which helped break down traditional 'clinician–patient' barriers.<sup>14</sup> The survey found innovative approaches in Recovery College courses for people with dementia, such as online delivery, which improved accessibility but also raised concerns about excluding those with limited computer literacy or resources. These findings shaped the direction of subsequent phases of the study.

Although prior research on Recovery College dementia courses was limited, the realist review analysed insights from broader Recovery College studies, and discussions with stakeholders enabled us to articulate what works, for whom and in what circumstances across the pathway of course development and delivery. The IPT highlighted the importance of coproduction and inclusive course delivery methods, the impact of stigma on access to course opportunities and the need to embed personal recovery principles throughout course development. Sustaining Recovery College courses and similar community peer-led initiatives is a challenge<sup>19,45</sup> as is the lack of specific NHS commissioning of Recovery Colleges, where post-diagnostic interventions are vulnerable due to NHS funding and resource constraints.<sup>46</sup> Evidence of how continued coproduction work with people who live with progressive conditions can be managed sensitively was also limited, likely due to the recent adoption of the Recovery model in the context of dementia. Most evidence related to motivations of coproducers with dementia becoming and continuing to be involved with courses, learning which could assist the recruitment of coproducers. Where coproduction is seen as a core characteristic of Recovery College courses,<sup>46,47</sup> description was limited in how coproduction is negotiated and facilitated between staff and people with dementia within the Recovery College model. Most evidence was generated together with our stakeholders with experience of coproducing courses. A

key factor affecting if and when people accessed support through Recovery Colleges was stigma, raised and discussed by people with dementia from the Partners in Research group. Experiences of shame and stigma have been associated with the avoidance of participating in activities and accessing health services.<sup>48,49</sup> These experiences may be compounded by attitudes, beliefs and perceptions related to mental health difficulties and further impact course attendance. Previous studies highlight that many people with dementia are uncomfortable attending mental health settings, preferring more familiar and less stigmatised locations.<sup>50,51</sup> This has implications for policy and practice for post-diagnostic services aiming to help people with these experiences when attendance is voluntary and dependent on a person seeking help rather than facilitated as part of care planning discussions following diagnosis. Methods for raising awareness of Recovery College dementia courses and encouraging people to attend will likely need to be multifaceted, with the relevance and benefits of the course to the person reinforced by trusted healthcare staff and peers. The review IPT established a foundation for the realist evaluation in WP2.

The realist evaluation developed programme theories providing causal explanations of what works how, why and for whom in Recovery College dementia courses, building on our IPT. Our findings highlight how Recovery College dementia courses can help challenge stigma, foster social inclusion and promote personal agency. Unlike other professional-led post-diagnostic support groups, recovery-focused courses create reciprocal learning spaces where people with dementia actively contribute rather than being positioned as care recipients. This aligns with research on peer support as a driver of recovery<sup>52</sup> but extends it by showing how peer-led learning enables meaning-making and identity reconstruction. Coproduced psychoeducation was an interactive, dynamic process, allowing flexible participation and 'in-the-moment' connectedness. Whether engaging in discussion, observation or non-verbal interaction, attendees were supported to take part at their own pace, reinforcing self-determination and empowerment.<sup>53,54</sup> These findings position Recovery College dementia courses as more than social engagement – they provide a platform for identity, agency and inclusion, counteracting the self-stigma and loss of confidence that often follow a dementia diagnosis.<sup>1</sup> The ability to share emotional material safely despite uncertainty emerged as a key process, where peer tutors modelled ways of managing challenges, reinforcing safe uncertainty<sup>55</sup> and helping attendees reframe their experiences. We identified barriers to equitable access, revealing that despite being open to all, courses did not

fully address the cognitive, cultural and socioeconomic factors that may limit engagement. With the numbers of people with dementia attending courses lower than anticipated, we identified perceptions of these barriers to access from health system and social perspectives drawing on candidacy theory,<sup>51</sup> which suggests that individuals assess their right to access services based on social and structural cues.

None of the five courses observed used systematic evaluation tools beyond basic course feedback sheets for measuring impact in a meaningful way. This highlights the need for use of validated outcome measures to assess course effectiveness and support long-term sustainability. While no measure examined in the scoping review in WP3 is currently validated for use in Recovery College dementia courses immediately, some measures, including the PPOM,<sup>42</sup> PPOM-C,<sup>43</sup> EID-Q<sup>18</sup> and CSES-8,<sup>44</sup> hold promise for further adaptation and validation. These tools could serve as starting points for the development of outcome measures that are more suited to the context of Recovery College dementia courses. However, further psychometric testing is needed to ensure that these measures are sensitive to the changes in personal recovery that occur as a result of attending or co-facilitating dementia courses.

### Strengths

Coproduction has been at the heart of this study, with the shared lived and learned expertise of the Partners in Research group, members of the staff advisory group and the research team. The study demonstrates how to work with people with dementia not only through PPIE activities but also as coresearchers and coproducers.

By using realist approaches, we are likely to have developed transferable learning about the setup and delivery of Recovery College dementia courses. This is because such approaches have enabled us to develop causal explanations that are based on widely occurring mechanisms. Our analyses have also unpacked the behaviour of these mechanisms under different contexts. However, while the ontological assumptions of realist approaches enable us to plausibly claim that our learning is indeed transferable, given the complexity of Recovery College dementia courses, further evaluation would be needed to confirm that our claims of transferability hold true.

### Challenges faced and limitations

The realist evaluation component of the study faced four primary challenges and limitations, all of which were related to data collection. The first was that we were only able to recruit four Recovery Colleges case sites instead

of the five we had originally intended. We had aimed to purposefully sample five Recovery College dementia courses at sites in England to reflect diversity, such as course delivery methods, socioeconomic and deprivation indices, urban/rural population mix, and areas with higher proportions of people from diverse ethnic and cultural backgrounds, to enable analyses to illuminate dementia courses in different contexts. Although only four sites and five courses were accessed, there was diversity in their geographical location, with a mix of urban and rural populations across the UK. There was diversity in course delivery methods and the length of delivery. Factors preventing us from securing a fifth site specifically to increase recruitment of people from diverse ethnic and cultural populations, included capacity issues within services, the absence of courses planned to run during the study period and some courses falling outside our scope, such as those designed exclusively for family supporters or those that were not co-facilitated with peer tutors. This meant that only two interviews were conducted with course attendees from cultural and ethnic minority backgrounds for the study and with no people living with dementia. However, one limitation was mitigated by the opportunity to observe one case site delivering the same course both online and in person. This allowed researchers to examine differences in course delivery methods while maintaining consistency in course content and structure. Observing both online and in-person courses provided valuable insights into how delivery mode influenced participant engagement, accessibility and interaction, offering a broader understanding of the practical and experiential differences between online and in-person Recovery College dementia courses. To address limitations in ethnic and cultural diversity of course attendees, we developed an online survey for healthcare professionals, service users and carers to complete to offer their views and experiences of considerations for ethnic minorities within Recovery College courses and wider dementia care pathways. This enabled us to include the perspectives of 54 more people in the work, including 23 people from ethnic and cultural minority groups.

A second challenge to data collection was that numbers of people with dementia attending the Recovery College courses observed were lower than anticipated. This raises important questions about awareness, signposting accessibility and perceived relevance of Recovery College dementia courses within statutory post-diagnostic support pathways.

Thirdly, systematic evaluation of the courses we observed was limited to standard Recovery College course feedback sheets. While anecdotal feedback from participants and

facilitators suggested positive experiences, there was no formal process in place to assess the course impact in a structured or meaningful way. This makes it difficult to measure the effectiveness and long-term benefits of these courses for people with dementia, their family supporters and staff involved in coproduction. The study attempted to address this gap in evaluation by conducting a scoping review of existing outcome measures for use on dementia courses. Despite the identification of several potentially useful measures, none have been explicitly validated for use in a Recovery College setting. The PPOM,<sup>39</sup> PPOM-C,<sup>41</sup> EID-Q<sup>42</sup> and CSES-8<sup>43</sup> demonstrate promising psychometric properties and align with important domains identified by DiSCOVERY stakeholders, yet they require further validation and adaptation before being implemented within dementia courses. No single measure captures all the meaningful domains, with many measures developed with minimal or no involvement of target users, raising concerns about content validity and relevance to people with dementia and their supporters. Many measures lacked strong psychometric evidence, particularly in terms of responsiveness, largely due to the absence of eligible intervention-based studies assessing their sensitivity to change. Additionally, criterion validity was often weak due to the lack of established gold standard measures in the domains of positive psychology and personal recovery within dementia research.

Finally, the evaluation lacked relevant data around processes of coproduction, which restricted its ability to confirm, refute or refine key theoretical propositions in realist review IPTs about financial instability, breaking down of traditional professional/client boundaries through coproduction or difficulties with shifting roles and identities. Additionally, we were unable to capture adequate healthcare staff data due to low numbers of attendees taking up the offer of interviews, therefore could not confirm if staff who respect coproducers' expertise can enhance their practice and whether staff attending courses co-facilitated by people with dementia gain deeper insight to living well with dementia and adopt a recovery-focused approach within their practice.

### ***Engagement with partners and stakeholders***

As has been reported throughout, this study was designed and conducted in close collaboration with people with dementia, family supporters and healthcare staff who played a crucial role in shaping study design, implementation and outputs. Stakeholders were actively engaged through advisory group activities, coproduction workshops and codelivery of talks discussing the study and sharing study findings, ensuring that the research

remains relevant and reflective of lived experiences. Research findings and project updates have been disseminated widely throughout the duration of the study with our partner organisations and stakeholders. A complete list of these activities can be found in [Appendix 2](#).

### Contribution to existing knowledge

This study provides the first systematic investigation of how Recovery Colleges can support people with dementia. It is the first to examine peer-led psychoeducation within the context of Recovery College dementia courses, which is a distinct and novel form of recovery-focused post-diagnostic dementia support. The national survey highlighted significant variations in course provision, revealing a lack of standardisation and a need for more consistent implementation. It also demonstrated the perceived benefits of coproduction while identifying key challenges, such as resource limitations and differing understandings of Recovery Colleges' role in dementia care. Building on these findings, the development of an IPT offers a structured framework to understand how Recovery College dementia courses operate, what factors influence their success and how they can be sustained within publicly funded mental health services. By integrating stakeholder perspectives and conducting a realist review, the study moves beyond description to provide an explanatory model that can inform future practice and policy. Together, these findings advance the field by offering both empirical evidence on the current landscape of Recovery College dementia courses and a theoretical foundation for refining and improving their implementation. This research lays the groundwork for further evaluation, ultimately shaping more effective, inclusive and sustainable post-diagnostic support for people living with dementia.

### Patient and public involvement and engagement

Patient and public involvement and engagement was delivered through an ongoing coproduction group who named themselves 'Partners in Research'. The group was made up of seven people with dementia and two family supporters and was facilitated by Rachael Litherland from national Community Interest Company 'Innovations in Dementia' ([www.innovationsindementia.org.uk/](http://www.innovationsindementia.org.uk/)). People who had personal experience of Recovery Colleges either as a peer tutor or as a course attendee, or had an interest in Recovery College courses for people with dementia, were recruited. As Irvin said: *'The only people who know what living with dementia is [like] are the people living with dementia'*.

There were two elements to the role of this group: (1) a PPIE role to help guide and influence the study by bringing views and ideas and commenting on the study and the study materials and (2) opportunities as a 'coproducer' and 'coresearcher'. The name 'Partners in Research' was adopted by the group to create a strong group dynamic and to signify the importance of power-sharing within the research relationship with the group.

The group met every 6–8 weeks over the lifetime of the study, meeting more regularly (up to fortnightly) in the latter stages as they became involved in coanalysis of the research data with members of the research team. The group were also involved in two larger stakeholder events. The Partners in Research carried out various activities, including:

- Giving feedback on the project website and publicity as well as research materials, including information sheets and consent forms.
- Speaking at conferences about the role and importance of a coproduction group including at the two Memory Services National Accreditation Programme (MSNAP) annual forums.
- Providing perspectives about how different research approaches could best be carried out 'in the field' with people with dementia and family supporters.
- Looking at the data that were emerging in the DiSCOVERY project and being involved in the analysis, particularly in relation to 'being a peer tutor' and 'involvement of family supporters'. This was a main activity for the final year of the project and required the Partners in Research to learn about some of the approaches in realist evaluation.
- Shaping the print guides and film that have been created to disseminate the learning from DiSCOVERY.

The impact of the Partners in Research group has been wide-ranging. A person with dementia from the DiSCOVERY Partners in Research group attended the ethics committee review meeting for the realist evaluation in WP2 alongside researchers. The study changed, step by step, with the recommendations and ideas that emerged from the group. One researcher regularly attended Partner in Research meetings and reported back to the group about what had changed in the study since the last meeting, because of their input. Each time she reported on at least four changes that had been made due to the group.

For example, researchers had more insight into the experiences of people with dementia when they were observing Recovery College dementia courses in action, because of the lived experiences that Partners in Research

shared. The group looked at the observation sheet that the researchers would use to record their observations, including atmosphere, group dynamics, the language used, non-verbal communication and the physical space. With their lived experiences, the group thought about ethnographic observation a bit differently. They reminded the researchers that it can be difficult to observe or 'see' what peoples' intentions are when they communicate. Observation is not objective. What you think you are seeing might not actually be what is intended. For example, Jacqui said: *'I've been told that initially I come across as argumentative until I settle in'*. She was worried that this might be recorded as anger when actually it would be vulnerability. Gerry added: *'I swear a lot, which you might misinterpret. But, for our group, this means we are at ease with each other!'*

The impact of being involved for Partners in Research has been positive, which they pin down to 'supportive facilitation', knowing that their views are not just being listened to but acted upon. As Allison said: *'Sometimes "Patient and Public Involvement" becomes a tick box exercise. It is great that this is considered more of a partnership'*.

As DiSCOVERY comes to an end, as well as shaping the dissemination materials, many Partners in Research have agreed to publicise the research outputs in the hope that more, high-quality Recovery College dementia courses will be available in the future.

## Equality, diversity and inclusion

### Background

The focus on people from diverse ethnic and cultural backgrounds as a separate WP in the DiSCOVERY study came from insights in recent literature reporting that, by 2026, there will be an estimated 50,000 people from diverse ethnic groups living with dementia in the UK, a figure rising much more rapidly than in the general population.<sup>56</sup> People from diverse ethnic and cultural backgrounds are under-represented in dementia services, often diagnosed later and less likely to receive cognitive assessments or post-diagnostic support, as found in studies that highlight the challenges and lack of provision to address language and cultural barriers.<sup>12,20</sup>

### Rationale

In January 2021, we undertook focus groups and interviews with family supporters of people from diverse ethnic and cultural backgrounds in preparation for the study. The family supporters expressed that it was important to include the voice of underserved groups in order to ensure that health research and service improvements

reflect groups' unique needs and outcomes. The groups spoke about the importance of incorporating cultural and life histories into the design of clinical interventions from the start of the research process. The groups raised that the impact of living with dementia is not openly discussed in certain underserved cultural groups and may lead to under-representation of stakeholders who are unwilling to speak to unknown professionals or non-family members about their lives. Due to these trends for people living with dementia from diverse ethnic and cultural backgrounds in the UK, it was felt important to focus on this issue within DiSCOVERY and establish if and how Recovery College dementia courses may be acceptable and inclusive as a route of post-diagnostic support for those from diverse backgrounds.

Initially, the intention was to pragmatically interview people from diverse backgrounds who were attending the Recovery College dementia courses recruited at the case sites. However, it quickly became apparent that few people from people from diverse ethnic and cultural backgrounds were involved in these courses as attendees or facilitators, and only two people were interviewed.

Therefore, we decided to examine some of the drivers for this poor engagement in Recovery College dementia courses and understand how courses could be adapted or consider cultural needs to increase engagement in minority groups. Additional data were collected, as described in [Methods](#), to understand the beliefs, attitudes and experiences of dementia care pathway from memory services onwards. This work aimed to understand the potential role that Recovery College dementia courses could play in supporting people from diverse ethnic and cultural backgrounds, barriers to attendance in current systems and identification of adaptations to approaches that could be made to support inclusion. Fifty-four healthcare professionals ( $n = 35$ ), carers ( $n = 14$ ) and people with dementia ( $n = 5$ ) completed a survey, consisting of 23 people from an ethnic minority background (42%). Using descriptive and content analysis, we analysed data from each of the three groups and across ethnic minority demographics. We found that there a high level of consensus on opinion and voices about the barriers facing ethnic minority groups in accessing Recovery Colleges and the adaptations needed to support inclusion. Therefore, data are presented as a collective voice across additional interview and survey work for WP5.

Key findings from this collective work suggest that Recovery Colleges need to consider specific cultural adaptations to meet their local population needs, such as introducing a social/reminiscence engagement event alongside the course for people from specific backgrounds,

holding whole-family courses for people from South Asian backgrounds or considering conducting courses in community centres to increase engagement. However, issues around translation and interpretation support were viewed as key barriers that required careful consideration to be inclusive for all attendees. In addition, it was shared by healthcare professionals working in memory services that they often did not promote Recovery College courses to people from diverse backgrounds, feeling that the service user or their family would not benefit from it. Going forward, it is important that Recovery College courses challenge some of these pre-conceptions with healthcare professionals who are responsible for promoting courses to service users and families. Details of themes and the EDI CMOCs generated from the combined interview and survey data are reported earlier.

## Impact and learning

### Dissemination

What have we done already to ensure the outcomes of the research are taken forward for implementation by stakeholders, partners and target audiences/groups, and what do we plan to do?

The coproduced guidance documents (WP4) will be shared in open access with:

- All Recovery Colleges in the UK.
- NHS memory services and dementia service leads involved in the study.
- Stakeholder organisations, including but not limited to the Royal College of Psychiatrists via MSNAP, the Dementia Engagement and Empowerment Project, the Alzheimer's Society, the British Psychological Society via the Faculty of Psychology of Older People.
- NIHR Applied Research Collaboration East of England (NIHR ARC EoE) study web page.
- ImROC will be informed of the study outcomes, offering potential for national-level influence.
- Presentations and summaries planned for future conferences and professional networks.
- Hosting of materials online.

### Longer term impact

Peer-led, psychoeducational courses about dementia within the Recovery College model could provide a cost-effective and sustainable model of post-diagnostic support, reducing the demand on clinical services and enabling services to reach more people. Clearer guidance on course delivery and evaluation may streamline the process for services to set up and

sustain courses. The study has identified factors that contribute to meaningful and empowering peer-led post-diagnostic support, offering potential to improve outcomes. The study has highlighted disparities in access for underserved populations of people from diverse ethnic and cultural backgrounds, positioning equity as a key focus for future practice and research.

### Lessons learned for future research

- The importance of building in additional time and resources for meaningful and sustained PPIE and coresearch activities.
- Future research should plan for greater flexibility to adapt to service pressures and external factors, particularly in identifying case sites.
- The need for improved recruitment and promotional strategies to reach under-represented groups and those from diverse backgrounds which meet the needs of the local population.
- Recognition that outcome measurement in this space remains challenging; future studies should prioritise the adaptation and validation of appropriate outcome measures.

## Implications for policy and decision-makers

Our findings indicate that dementia support through Recovery Colleges is an emerging form of post-diagnostic support to complement therapeutic approaches such as Cognitive Stimulation Therapy or medication. It offers a distinct alternative recovery-focused, psychoeducational approach to other professional-led post-diagnostic support groups and courses that would be reasonable to support and fund.

The provision of Recovery College dementia courses aligns with policy priorities around personalised, recovery-focused dementia care and contributes to reducing stigma, promoting self-management and influencing outcomes such as hope, coping, empowerment, resilience and self-efficacy. The key idea of personal recovery applied and experienced here can be seen as essential to deliver a person-centred approach to post-diagnostic support pathways. Recovery College dementia courses can help neutralise the impacts of stigma, as public and policy-makers increasingly recognise how 'personal recovery' is relevant and important for people to adjust and live positively following a diagnosis of dementia.

The guidance resources codeveloped in WP4 offer practical recommendations for commissioners, service leaders and practitioners to support integrating and

sustaining Recovery College dementia courses within local dementia care pathways, and these are presented here:

- Work with local Recovery Colleges to support promotion and awareness raising of locally run Recovery College dementia courses across the health and social care system, including general practitioners.
- Assist memory and dementia service leaders with Integrated Care Board-level health data to help understand local populations and post-diagnostic support needs, as this may influence how courses are commissioned, designed and delivered.
- Help Recovery Colleges involved in supporting dementia courses identify potential sustainable sources of funding for any additional costs associated with the inclusivity and running of courses, for example room hire, transport, interpreters, refreshments and printed materials.

However, there needs to be careful consideration of course content within courses with mixed attendees of people with dementia, family and staff to ensure that content does not marginalise or disempower the person with dementia, such as a predominant focus of carer burden.

## Research recommendations

We make five recommendations for further research and which could inform future funding calls:

- 1 The scoping review revealed a lack of validated outcome measures for evaluating Recovery College dementia courses. A more robust evaluation framework is required to capture both qualitative and quantitative outcomes that reflect the real-life benefits of these courses. This will not only strengthen the evidence for their effectiveness but also support efforts to secure dedicated funding for recovery-focused post-diagnostic support.
- 2 Recovery Colleges should consider ways to make dementia courses more culturally inclusive and accessible to diverse socioeconomic and geographical areas, that is rural communities. Future research should explore how Recovery College dementia courses can better engage diverse communities, ensuring that more people feel able to participate.
- 3 The coproduced guidance resources developed in WP4 should be. There is potential to explore how the guidance documents produced from this research can be applied in other voluntary or community-based settings as an alternative to being recognised as supporting the delivery of dementia courses within the scope of Recovery

Colleges. Understanding how these principles translate across different models of support will be essential for expanding access to recovery-focused post-diagnostic interventions.

- 4 Understanding how to encourage individuals living with dementia experiencing stigma and shame to access post-diagnostic support is an important aspect of future research. The development of Recovery College dementia courses has involved stakeholders with lived and professional experience, and continued theory development is necessary to establish how courses can reach individuals struggling to reconcile their future alongside dementia and how people living with dementia can be supported emotionally and practically to coproduce and attend courses.
- 5 To support sustainable commissioning of Recovery College dementia courses, future research should include a formal economic evaluation. While the qualitative and lived experience data from this study demonstrate meaningful outcomes for people with dementia and their family supporters, commissioners and decision-makers require evidence of cost-effectiveness to justify longer-term investment.

## Conclusions

This study highlights the benefits of running Recovery College courses with and for people with dementia. Identifying that the activity between peer tutors with dementia and course attendees foregrounds firmly centres the voice and experiences of those living with dementia. There is robust evidence that Recovery Colleges align with recovery principles for people living with dementia by promoting self-management, meaningful engagement and personal growth. A distinctive feature of courses is that they are instigated and developed by highly motivated individuals rather than a standardised 'one-size-fits-all' course; however, there are risks with this as key tutors are not available. This study highlights the need for a nuanced approach to evaluating Recovery College dementia courses, particularly in measuring meaningful outcome domains for people attending. For the model to be more widely commissioned, there may need to be further validation of existing outcome measures, or development of more sensitive outcomes to evaluate short-, medium- and long-term outcomes for all attendee groups. There remains a need to address the limited involvement of people from ethnic minority communities. Barriers within dementia care pathways, alongside societal expectations around family members as primary supporters and mistrust in services, may limit engagement.

As statutory mental health trusts continue to face financial pressures and increasing demand, we may see voluntary and community groups offering similar personal recovery-focused courses. This will provide opportunity to examine if attendees experience similar challenges in access as they did within the cases we included. Our approach and close working with stakeholders encourage confidence that the results and resources we have codeveloped will enable other health and social care staff to work with people with lived experience of dementia to coproduce courses.

## Additional information

### CRedit contribution statement

**George Christopher Fox** (<https://orcid.org/0000-0001-9480-5704>): Conceptualisation, Funding acquisition, Methodology, Investigation, Resources, Formal analysis, Project administration, Supervision, Writing – reviewing and editing.

**Juniper West** (<https://orcid.org/0000-0003-0802-7243>): Conceptualisation, Funding acquisition, Methodology, Investigation, Resources, Data curation, Formal analysis, Project administration, Visualisation, Writing – original draft, Writing – reviewing and editing.

**Thomas Rhodes** (<https://orcid.org/0000-0002-3992-0280>): Resources, Project administration, Writing – original draft, Writing – reviewing and editing.

**Fiona Poland** (<https://orcid.org/0000-0003-0003-6911>): Conceptualisation, Funding acquisition, Methodology, Investigation, Formal analysis, Writing – reviewing and editing.

**Linda Birt** (<https://orcid.org/0000-0002-4527-4414>): Conceptualisation, Funding acquisition, Methodology, Investigation, Data curation, Formal analysis, Writing – original draft, Writing – reviewing and editing.

**Melanie Handley** (<https://orcid.org/0000-0002-8037-5042>): Conceptualisation, Methodology, Investigation, Data curation, Formal analysis, Visualisation, Writing – original draft, Writing – reviewing and editing.

**Geoff Wong** (<https://orcid.org/0000-0002-5384-4157>): Conceptualisation, Funding acquisition, Methodology, Data curation, Formal analysis, Writing – reviewing and editing.

**Esme Moniz-Cook** (<https://orcid.org/0000-0002-7232-4632>): Conceptualisation, Funding acquisition, Methodology, Investigation, Formal analysis, Writing – reviewing and editing.

**Emma Wolverson** (<https://orcid.org/0000-0002-5789-7862>): Conceptualisation, Formal analysis, Methodology, Writing – original draft, Writing – reviewing and editing.

**Bonnie Teague** (<https://orcid.org/0000-0002-3248-2257>): Conceptualisation, Funding acquisition, Methodology, Investigation, Resources, Formal analysis, Writing – original draft, Writing – reviewing and editing.

**Corinna Hackmann** (<https://orcid.org/0000-0002-4940-6998>): Conceptualisation, Funding acquisition, Methodology, Formal analysis, Writing – reviewing and editing.

**Rachael Litherland** (<https://orcid.org/0009-0003-9747-6207>): Conceptualisation, Funding acquisition, Methodology, Investigation, Resources, Formal analysis, Project administration, Writing – original draft, Writing – reviewing and editing.

**Leanne Hague** (<https://orcid.org/0000-0002-4711-959X>): Investigation, Resources, Data curation, Formal analysis, Project administration, Writing – original draft, Writing – reviewing and editing.

**Jarin Alam** (<https://orcid.org/0009-0007-3135-6260>): Investigation, Resources, Data curation, Formal analysis, Project administration, Writing – original draft, Writing – reviewing and editing.

**Kathryn Sams** (<https://orcid.org/0009-0008-6799-4720>): Conceptualisation, Funding acquisition, Investigation, Writing – reviewing and editing.

**Ruth Mills** (<https://orcid.org/0000-0002-0710-5193>): Conceptualisation, Funding acquisition, Investigation, Writing – reviewing and editing.

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### Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

### Ethics statement

The WP1 was reviewed by West Midlands – Coventry and Warwickshire Research Ethics Committee (22/WM/0021) and received HRA and Health and Care Research Wales (HCRW) approval on 16 March 2022. WPs 2–4 were also reviewed by West Midlands – Coventry and Warwickshire Research Ethics Committee (22/WM/0215) and received HRA and Health and Care Research Wales (HCRW) approval on 28 October 2022.

### Information governance statement

Norfolk and Suffolk NHS Foundation Trust (NSFT) is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under Data Protection legislation NSFT is the Data Processor and Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here: [www.nsft.nhs.uk/research-compliance-and-policies/](http://www.nsft.nhs.uk/research-compliance-and-policies/).

### Disclosure of interests

**Full disclosure of interests:** Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/GJCF2730>.

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Geoff Wong has received no other funding for this study but currently holds other awards with the NIHR, Wellcome Trust, The Joyce Morris Research Programme and UK Research and Innovation. Geoff Wong has been a member of the UK's National Institute for Health and Care Research (NIHR) Health Technology Assessment programme, Prioritisation Committee A Methods Group and Post-Funding Committee teleconferences (POC members).

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This synopsis was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

### Study registration

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### Award publications

This synopsis provided an overview of the research award *Post-Diagnostic Dementia Support within the ReCOVERY College Model: A Realist Evaluation (DiSCOVERY)*.

Other articles published as part of this thread are:

West J, Birt L, Wilson D, Mathie E, Poland F. 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. *Front Rehabil Sci.* 2022;3. <https://doi.org/10.3389/fresc.2022.920496>

Wolverson E, Hague L, West J, Teague B, Fox C, Birt L, *et al.* Building an initial understanding of UK Recovery College dementia courses: a national survey of Recovery College and memory services staff. *WWOP* 2025;28:108–19. <https://doi.org/10.1108/WWOP-02-2023-0003>

Handley M, Wheeler C, Duddy C, Wong G, Birt L, Fox C, *et al.* Operationalising the Recovery College model with people living with dementia: a realist review. *Aging Ment Health* 2024;25. <https://doi.org/10.1080/13607863.2024.2356878>

Birt L, Handley M, West J, Alam J, Poland F, Moniz-Cook E, *et al.*; DISCOVERY study team. Role of peer-tutors with dementia in Recovery College dementia courses: an ethnographic account. *Gerontologist* 2026 Feb 15:gnag010. <https://doi.org/10.1093/geront/gnag010>

Alam J, West J, Miniz-Cook E, Wolverson E, Handley M, Birt L, *et al.* A scoping review of outcome measures for people living with dementia and family supporters to evaluate Recovery College dementia courses. *Front Psychiatry* 2025;16. <https://doi.org/10.3389/fpsyt.2025.1591772>

For more information about this research, please view the award page ([www.fundingawards.nihr.ac.uk/award/NIHR131676](http://www.fundingawards.nihr.ac.uk/award/NIHR131676)).

### Additional outputs

The full list can be found in [Table 1](#) and [Appendix 2, Table 4](#).

### About this synopsis

The contractual start date for this research was in January 2022. This synopsis began editorial review in April 2025 and was accepted for publication in September 2025. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The Health and Social Care Delivery Research editors and publisher have tried to ensure the accuracy of the authors' article and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this synopsis.

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### Glossary

**CHIME framework** A conceptual framework for personal recovery which encompasses five interconnected components: **C**onnectedsness, **H**ope and optimism, **I**ntity, **M**eaning and purpose and **E**mpowerment.

**Context–Mechanism–Outcome–Configuration** A diagrammatic or narrative description offering an explanation of the relationship between some particular Context(s), Mechanism(s) and Outcome(s). Multiple Context(s), Mechanism(s) and Outcome(s) may exist within a single programme theory.

**Partners in Research** A group consisting of people with dementia and family supporters, aimed at guiding and influencing the research through patient and public involvement and engagement activities and coproduction.

**Programme Theory** A theory that describes what an intervention comprises and how it is expected to work, or the process by which the outcomes of interest are thought to come about (expressed as a narrative description or in a diagram). A realist programme theory is expressed in terms of the relationships between relevant Context(s), Mechanism(s) and Outcome(s) and the relations between relevant Context(s), Mechanism(s) and Outcome(s).

**Psychoeducation** A structured learning approach that provides individuals and their family supporters with information and support to better understand and manage mental health conditions, which goes beyond simply sharing information; it aims to empower individuals by teaching them about their diagnosis, symptoms, treatment options and coping strategies.

**Realist evaluation** A theory-driven approach to evaluation that seeks to understand what works, for whom, under what circumstances and how. It focuses on the mechanisms through which outcomes are achieved and the context in which these mechanisms operate

**Realist methodology** An approach to research and evaluation that focuses on understanding how and why complex interventions work in specific contexts. It involves identifying the underlying mechanisms that generate outcomes and the contextual factors that influence these mechanisms

**Realist review** A type of systematic review that aims to understand how and why complex interventions work (or do not work) in particular contexts.

## List of abbreviations

ARC EoE	Applied Research Collaboration East of England
CHIME	Connecting with others, inspiring Hope, maintaining a positive Identity, finding Meaning in life outside of symptoms and Empowerment and control over life with a focus on strengths
CMOC	Context–Mechanism–Outcome–Configuration
COVID-19	coronavirus disease discovered in 2019
CSES-8	8-item Caregiver Self-Efficacy Scale
EDI	equality, diversity and inclusion
EID-Q	Engagement and Independence in Dementia Questionnaire
ImROC	Implementing Recovery through Organisational Change
IPT	initial programme theory
MSNAP	Memory Services National Accreditation Programme
PPIE	patient and public involvement and engagement
PPOM	positive psychology outcome measure
WP	work package

## References

- Perkins R, Hill L, Daley S, Chappell M, Rennison J. 'Continuing to be me': recovering a life with a diagnosis of dementia. *ImROC* 2016;1–36. URL: <https://static1.squarespace.com/static/65e873c27971d37984653be0/t/668c44f1a8edf7462ab02bb1/1720468722651/Continuing-to-be-me-recovery-and-dementia-briefing-Sept-2016.pdf> (accessed 25 February 2025).
- Alzheimer's Disease International. *World Alzheimer Report 2019: Attitudes to Dementia*. URL: [www.alzint.org/u/WorldAlzheimerReport2019.pdf](http://www.alzint.org/u/WorldAlzheimerReport2019.pdf) (accessed 25 February 2025).
- Birt L, Griffiths R, Charlesworth G, Higgs P, Orrell M, Leung P, Poland F. Maintaining social connections in dementia: a qualitative synthesis. *Qual Health Res* 2020;**30**:23–42. <https://doi.org/10.1177/1049732319874782>
- Bamford C, Wheatley A, Brunskill G, Booi L, Allan L, Banerjee S, et al.; PriDem study team. Key components of post-diagnostic support for people with dementia and their carers: a qualitative study. *PLOS ONE* 2021;**16**:e0260506. <https://doi.org/10.1371/journal.pone.0260506>
- National Institute for Health and Care Excellence (NICE). *Dementia: Assessment, Management and Support for People Living with Dementia and Their Carers (ng97)*. 2018. URL: [www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109](http://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109) (accessed 25 February 2025).
- Jethwa J, Hunter-Brown H, Senkoy A. *Memory Services National Accreditation Programme (MSNAP) Standards: Standards for Memory Services*. London; 2024. URL: [www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---9th-edition-\(2024\).pdf?sfvrsn=8c42ae6c\\_3](http://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---9th-edition-(2024).pdf?sfvrsn=8c42ae6c_3) (accessed 25 February 2025).
- Department of Health and Social Care. *Dementia 2020 Challenge: 2018 Review Phase 1*. URL: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/780777/dementia-2020-challenge-2018-review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/780777/dementia-2020-challenge-2018-review.pdf) (accessed 25 February 2025).
- van Horik JO, Collins R, Martyr A, Henderson C, Jones RW, Knapp M, et al.; IDEAL Programme Team. Limited receipt of support services among people with mild-to-moderate dementia: findings from the IDEAL cohort. *Int J Geriatr Psychiatry* 2022;**37**:1–8. <https://doi.org/10.1002/gps.5688>

9. Wheatley A, Bamford C, Brunskill G, Harrison Denning K, Allan L, Rait G, Robinson L. Task-shifted approaches to post-diagnostic dementia support: a qualitative study exploring professional views and experiences. *BMJ Open* 2020;**10**:e040348–8. <https://doi.org/10.1136/bmjopen-2020-040348>
10. Low LF, Swaffer K, McGrath M, Brodaty H. Do people with early stage dementia experience prescribed disengagement™? A systematic review of qualitative studies. *Int Psychogeriatr* 2018;**30**:807–31.
11. Vince A, Clarke C, Wolverson E. The meaning and experience of well-being in dementia for psychiatrists involved in diagnostic disclosure: a qualitative study. *Int Psychogeriatr* 2017;**29**:93–104.
12. Nielsen TR, Nielsen DS, Waldemar G. Barriers to post-diagnostic care and support in minority ethnic communities: a survey of Danish primary care dementia coordinators. *Dementia* 2020;**19**:2702–13.
13. Lowen C, Birt L, West J. Recovery colleges and dementia courses – a scoping survey. *Ment Health Soc Incl* 2019;**23**:166–72. <https://doi.org/10.1108/MHSI-08-2019-0024>
14. West J, Birt L, Wilson D, Mathie E, Poland F. 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. *Front Rehabil Sci* 2022;**3**:920496. <https://doi.org/10.3389/fresc.2022.920496>
15. Birt L, West J, Poland F, Wong G, Handley M, Litherland R, et al. Protocol for a realist evaluation of recovery college dementia courses: understanding co-production through ethnography. *BMJ Open* 2023;**13**:e078248. <https://doi.org/10.1136/bmjopen-2023-078248>
16. Wolverson E, Hague L, West J, Teague B, Fox C, Birt L, et al. Building an initial understanding of UK recovery college dementia courses: a national survey of recovery college and memory services staff. *Working Older People* 2024;**28**:108–19. <https://doi.org/10.1108/WWOP-02-2023-0003>
17. Handley M, Wheeler C, Duddy C, Wong G, Birt L, Fox C, et al. Operationalising the recovery college model with people living with dementia: a realist review. *Aging Ment Health* 2024;**28**:1078–89. <https://doi.org/10.1080/13607863.2024.2356878>
18. Alam J, West J, Moniz-Cook E, Wolverson E, Handley M, Birt L, Fox C. A scoping review of outcome measures for people living with dementia and family supporters to evaluate Recovery College dementia courses. *Front Psychiatry* 2025;**16**. <https://doi.org/10.3389/fpsy.2025.1591772>
19. Birt L, Handley M, West J, Alam J, Poland F, Moniz-Cook E, et al.; DiSCOVERY study team. Role of peer-tutors with dementia in Recovery College dementia courses: an ethnographic account. *Gerontologist* 2026 Feb 15:gnag010. <https://doi.org/10.1093/geront/gnag010>
20. Dodd E, Pracownik R, Popel S, Collings S, Emmens T, Cheston R. Dementia services for people from black, Asian and minority ethnic and White-British communities: does a primary care based model contribute to equality in service provision? *Health Social Care Community* 2020:1–9.
21. NHS England. *How Co-Production Is Used to Improve the Quality of Services and People's Experience of Care: A Literature Review*. 2023. URL: [www.england.nhs.uk/long-read/how-co-production-is-used-to-improve-the-quality-of-services-and-peoples-experience-of-care-a-literature-review/](http://www.england.nhs.uk/long-read/how-co-production-is-used-to-improve-the-quality-of-services-and-peoples-experience-of-care-a-literature-review/) (accessed 25 February 2025).
22. Perkins R, Meddings S, Williams S, Repper J. *Recovery Colleges 10 Years On*. ImROC; 2018. URL: [www.imroc.org/publications/recovery-colleges-10-years-on](http://www.imroc.org/publications/recovery-colleges-10-years-on) (accessed 25 February 2025).
23. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry* 2011;**199**:445–52. <https://doi.org/10.1192/bjp.bp.110.083733>
24. Recollect Study Team. *Recollect study results*. URL: [www.researchintorecovery.com/research-recollect-findings/](http://www.researchintorecovery.com/research-recollect-findings/) (accessed 25 February 2025).
25. King T, Meddings S. Survey identifying commonality across international recovery colleges. *Ment Health Soc Incl* 2019;**23**:121–8. <https://doi.org/10.1108/MHSI-02-2019-0008>
26. Perkins R, Repper J, Rinaldi M, Brown H. *Implementing Recovery through Organisational Change: Briefing Paper*. Centre for Mental Health; 2012. URL: <https://static.squarespace.com/static/65e873c27971d37984653be0/t/668cedec6ea5392f6ac0ef31/1720511981544/1.Recovery-Colleges.pdf> (accessed 25 February 2025).
27. Francis R. *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary*. The Stationery Office; 2013. URL: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/279124/0947.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/279124/0947.pdf) (accessed 25 February 2025).
28. Sommer J, Gill K, Stein-Parbury J. Walking side-by-side: Recovery Colleges revolutionising mental health care. *Ment Health Soc Incl* 2018;**22**:18–26. <https://doi.org/10.1108/MHSI-11-2017-0050>
29. Meddings S, McGregor J, Roeg W, Shepherd G. Recovery colleges: quality and outcomes. *Ment Health*

- Soc Incl* 2015;**19**:212–21. <https://doi.org/10.1108/MHSI-08-2015-0035>
30. Zabel E, Donegan G, Lawrence K, French P. Exploring the impact of the recovery academy: a qualitative study of recovery college experiences. *J Ment Health Train Educ Pract* 2016;**11**:162–71. <https://doi.org/10.1108/JMHTEP-12-2015-0052>
  31. Cheffey J, Hill L, McCullough C, McCullough C. 'Can I facilitate a project when my memory lets me down?': the challenges and rewards of co-producing a 'living well with dementia' course. *Fpop Bull* 2017;**1**:19–25.
  32. Emrich-Mills L, Hammond LL, Rivett E, Rhodes T, Richmond P, West J. Identifying research priorities for older people's mental health services. *Ment Health Soc Incl* 2019;**23**:89–100. <https://doi.org/10.1108/MHSI-02-2019-0004>
  33. Department of Health. *Living Well with Dementia: A National Dementia Strategy*. 2009. URL: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168220/dh\\_094051.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf) (accessed 25 February 2025).
  34. Downs M, Lord K. Person-centred dementia care in the community: a perspective from the United Kingdom. *J Gerontol Nurs* 2017;**43**:11–7. <https://doi.org/10.3928/00989134-20170515-01>
  35. Miro. *Miro Online Whiteboard (No Version Provided)*. RealTimeBoard; 2022. URL: [www.miro.com](http://www.miro.com) (accessed 25 February 2025).
  36. Dufault K, Martocchio BC. Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *Nurs Clin North Am* 1985;**20**:379–91.
  37. Kitwood, T. *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press; 1997.
  38. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;**24**:105–12. <https://doi.org/10.1016/j.nedt.2003.10.001>.
  39. Stoner CR, Orrell M, Spector A. The positive psychology outcome measure (PPOM) for people with dementia: psychometric properties and factor structure. *Arch Gerontol Geriatr* 2018;**76**:182–7. <https://doi.org/10.1016/j.archger.2018.03.001>
  40. Terwee CB, Bot SD, de Boer MR, van der Windt DAWM, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol* 2007;**60**:34–42. <https://doi.org/10.1016/j.jclinepi.2006.03.012>
  41. Pione RD, Stoner CR, Cartwright AV, Spector A. Measuring hope and resilience in carers of people living with dementia: the positive psychology outcome measure for carers (PPOM-C). *Dementia* 2023;**22**:978–94. <https://doi.org/10.1177/14713012231165113>
  42. Stoner CR, Orrell M, Spector A. Psychometric properties and factor analysis of the engagement and independence in dementia questionnaire (EID-Q). *Dement Geriatr Cogn Disord* 2018;**46**:119–27. <https://doi.org/10.1159/000488484>
  43. Ritter PL, Sheth K, Stewart AL, Gallagher-Thompson D, Lorig K. Development and evaluation of the eight-item caregiver self-efficacy scale (CSES-8). *Gerontologist* 2022;**62**:e140–9. <https://doi.org/10.1093/geront/gnaa174>
  44. Pham TM, Petersen I, Walters K, Raine R, Manthorpe J, Mukadam N, Cooper C. Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data. *Clin Epidemiol* 2018;**10**:949–60. <https://doi.org/10.2147/CLEP.S152647>
  45. Morton T, Wong G, Atkinson T, Brooker D. Sustaining community-based interventions for people affected by dementia long term: the SCI-Dem realist review. *BMJ Open* 2021;**11**:e047789. <https://doi.org/10.1136/bmjopen-2020-047789>
  46. Hayes D, Camacho EM, Ronaldson A, Stepanian K, McPhilbin M, Elliott RA, et al. Evidence-based Recovery Colleges: developing a typology based on organisational characteristics, fidelity and funding. *Soc Psychiatry Psychiatr Epidemiol* 2024;**59**:759–68. <https://doi.org/10.1007/s00127-023-02452-w>
  47. Toney R, Knight J, Hamill K, Taylor A, Henderson C, Crowther A, et al. Development and evaluation of a Recovery College fidelity measure. *Can J Psychiatry* 2019;**64**:405–14. <https://doi.org/10.1177/0706743718815893>
  48. Aldridge H, Fisher P, Laidlaw K. Experiences of shame for people with dementia: an interpretative phenomenological analysis. *Dementia* 2019;**18**:1896–911. <https://doi.org/10.1177/1471301217732430>
  49. Ryan L. Accessing community dementia care services in Ireland: emotional barriers for caregivers. *Health Soc Care Community* 2021;**29**:1980–9. <https://doi.org/10.1111/hsc.13342>
  50. Stephan A, Bieber A, Hopper L, Joyce R, Irving K, Zanetti O, et al.; Actifcare Consortium. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC Geriatr* 2018;**18**:131. <https://doi.org/10.1186/s12877-018-0816-1>
  51. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, et al. Conducting a critical interpretive synthesis of the literature on access

- to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006;**6**:35. <https://doi.org/10.1186/1471-2288-6-35>
52. Toney R, Elton D, Munday E, Hamill K, Crowther A, Meddings S, *et al.* Mechanisms of action and outcomes for students in recovery colleges. *Psychiatr Services* 2018;**69**:1222–9. <https://doi.org/10.1176/appi.ps.201800283>
53. Reid N, Khan B, Soklaridis S, Kozloff N, Brown R, Stergiopoulos V. Mechanisms of change and participant outcomes in a Recovery Education Centre for individuals transitioning from homelessness: a qualitative evaluation. *BMC Public Health* 2020;**20**:497. <https://doi.org/10.1186/s12889-020-08614-8>
54. van Corven CTM, Bielderma A, Wijnen M, Leontjevas R, Lucassen PLBJ, Graff MJL, Gerritsen DL. Empowerment for people living with dementia: an integrative literature review. *Int J Nurs Stud* 2021;**124**:104098. <https://doi.org/10.1016/j.ijnurstu.2021.104098>
55. Mason B. Towards positions of safe uncertainty. *Hum Syst* 2022;**2**:54–63. <https://doi.org/10.1177/26344041211063125>
56. All Party Parliamentary Group on Dementia. *Report: Dementia Does Not Discriminate*. 2013. URL: [www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg\\_2013\\_bame\\_report.pdf](http://www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf) (accessed 25 February 2025).
57. Birt L, Fox C, Alam J, Wong G, Handley M, Teague B, *et al.* Co-produced, peer supported post-diagnostic dementia support: a realist evaluation of Recovery College courses. *Research Square* 2025. <https://doi.org/10.21203/rs.3.rs-7145910/v1>

Appendix 1

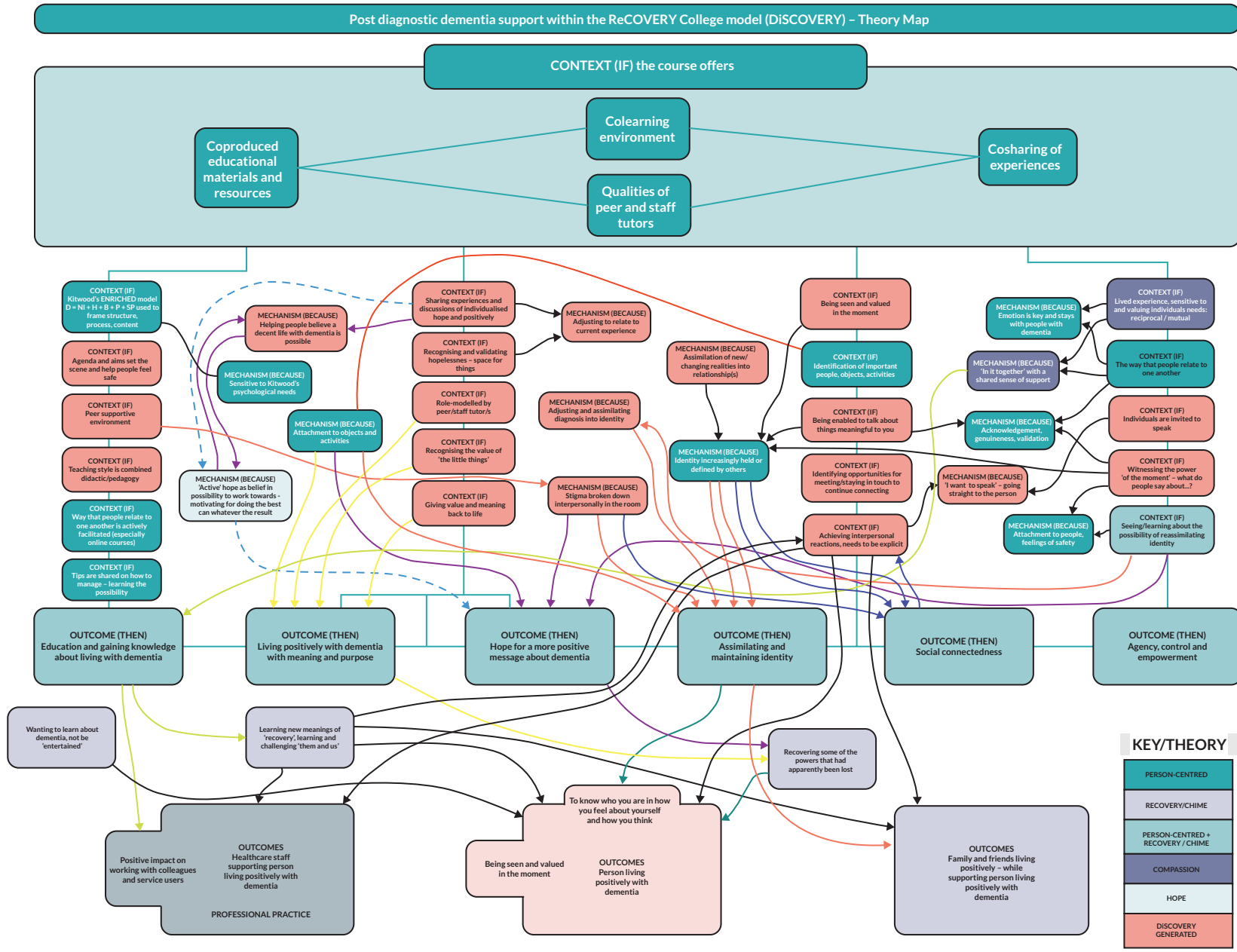


FIGURE 2 Map of conceptual models explaining collaborative and interactive processes in Recovery College dementia courses.<sup>35</sup>

## Appendix 2

TABLE 4 DiSCOVERY communications, outputs and dissemination log

Year 1			2021–2	
When	Format	Title	Who	Audience/outputs
15 October 2021	Talk	Recovery models	Chris Fox	INTERDEM Academy and DISTINCT School in Nottingham on behalf of Maastricht University. Audience: 15 early stage researchers (PhDs) working in the field of dementia and technology, and 10 early career researchers (PhD's and post-docs from INTERDEM Academy) working in the field of dementia and psychosocial interventions
4 November 2021	Seminar	Post-Diagnostic Dementia Support within the ReCOVERY College Model (DiSCOVERY)	Chris Fox Juniper West Linda Birt	Norfolk and Suffolk NHS Foundation Trust (NSFT) Older People's Services research seminar <a href="https://www.youtube.com/watch?v=yjcibcGtXH4">www.youtube.com/watch?v=yjcibcGtXH4</a>
24 November 2022	Podcast	Recovering hope after a diagnosis of dementia	Claire Mutimer Chris Fox Juniper West	<a href="https://x.com/NSFTresearch/status/1463417360291876865">https://x.com/NSFTresearch/status/1463417360291876865</a>
3 March 2022	Talk	DiSCOVERY: a realist evaluation	Chris Fox Juniper West	NSFT North Norfolk and Norwich memory services team away day
15 March 2022	Talk	DiSCOVERY: a realist evaluation	Juniper West	East Suffolk community memory assessment services team meeting, presentation from this month's NSFT OP Forum shared at team's request
20 April 2022	Press release	Study and WP1 survey launch	Claire Mutimer	With short introductory film DiSCOVERY survey film – YouTube DiSCOVERY web page <a href="http://www.nsft.nhs.uk/discovery-study">www.nsft.nhs.uk/discovery-study</a> and Twitter at NSFT Research via @NSFTResearch
26 April 2022	News article	Study offers hope after dementia diagnosis	NIHR Dementia Researcher	Study offers hope after dementia diagnosis ( <a href="http://nhr.ac.uk">nhr.ac.uk</a> ) (8 likes)
26 April 2022	Re-Tweets	Study offers hope after dementia diagnosis	NIHR Dementia Researcher	By Adam Smith, Programme Manager, NIHR Dementia Researcher (8900 followers)
10 May 2022	News article	Recovery Colleges	Journal of Dementia Care	Recovery colleges – <i>Journal of Dementia Care</i>
20 May 2022	Radio interview	DiSCOVERY study mention	Emma Wolverson	BBC Radio Humberside for dementia awareness week, focus on local support and issues but referenced DiSCOVERY, BBC Sounds – Radio Humberside David Burns Show (Fiona Mills sitting in) about 10 minutes into the show
20 May 2022	News article	DiSCOVERY study	Linda Birt Fiona Poland Juniper West	NIHR Applied Research Collaborative (ARC) East of England The DiSCOVERY Study: Post-Diagnostic Dementia Support within the Recovery College Model   ARC East of England ( <a href="http://nhr.ac.uk">nhr.ac.uk</a> )
16 June 2022	Event	'Living well with dementia' course group – award finalists	NSFT Staff Excellence Awards Juniper West Bonnie Teague	Nominated East Suffolk 'Living well with dementia' course group – DiSCOVERY local PPIE contributors and East Suffolk memory service team – finalists in the NSFT Staff Excellence Awards 2022 in the Research and Evidence Impact Award category

continued

TABLE 4 DiSCOVERY communications, outputs and dissemination log (continued)

Year 1				2021–2
When	Format	Title	Who	Audience/outputs
22 June 2022	Article	Case study of coproduction within a Recovery College dementia course	Juniper West Linda Birt Fiona Poland	JW NIHR CLAHRC research fellowship output – Citation: <sup>13</sup> <a href="#">Table 1</a>
24 June 2022	Talk	ImROC Recovery Colleges Learning Set	Linda Birt	71 practitioners from Recovery Colleges across UK and someone from the Netherlands for Researchfish
9 August 2022	Repeat news article	NIHR ARC Bulletin	Linda Birt Fiona Poland	New project to offer hope after a diagnosis of dementia   ARC East of England (nhr.ac.uk)
03 November 2022	Talk	Humber Teaching NHS Foundation Trust Annual Research Conference	Emma Wolverson Leanne Hague	Presentation of WP 1a staff survey results
Year 2				2023
When	Format	Title	Who	Audience/outputs
14 February 2023	Panel	CareCoach and DiSCOVERY studies dementia and recovery panel discussion	Chris Fox Juniper West Peter Berry Deb Bunt + CareCoach study staff	81 general public audience members: Norwich Science Festival at The Forum in Norwich <a href="https://norwichsciencefestival.co.uk/news/science-festival-returns-for-february-half-term-2023">https://norwichsciencefestival.co.uk/news/science-festival-returns-for-february-half-term-2023</a>
13 March 2023	News	DiSCOVERY newsletter (1)	Leanne Hague	Study newsletter first edition sent to stakeholder groups and interested parties
16/17 March 2023	Talk/discussion	Recovery Colleges and social prescribing in dementia – what is it all about?	Chris Fox	Royal College of Psychiatrists Conference (DiSCOVERY and SPLENDID studies)
23 June 2023	News	DiSCOVERY newsletter (2)	Leanne Hague	Study newsletter second edition sent to stakeholder groups and interested parties
29 June 2023	Talk	DiSCOVERY + WP1a survey findings	Chris Fox Juniper West	NSFT Research Showcase Conference
29 June 2023	Web page	ARC Bite	Leanne Hague	Study summary page for ARC EoE website
5 July 2023	Poster	A rapid realist review of coproducing and co-facilitating Recovery College dementia courses	Charlotte Wheeler Juniper West	Poster presentation at British Society of Gerontology 52nd Annual Conference hosted by the University of East Anglia, Norwich
16–20 July 2023	Poster	A rapid realist review of coproducing and co-facilitating Recovery College dementia courses	Melanie Handley	Poster presentation at Alzheimer's Association International Conference (AAIC) <sup>®</sup> Online
25 July 2023	Article	WP1a survey findings	Emma Wolverson	Citation: <sup>16</sup> <a href="#">Table 1</a>
26 September 2023	Talk/discussion	DiSCOVERY study	Juniper West Tom Rhodes	With Bronte Heath and colleagues from the Alzheimer's Society Research Evidence team
12 October 2023	Talk	DiSCOVERY study	Chris Fox Rachael Litherland Martin Robertson	MSNAP 14th Annual Forum (online); <a href="https://youtu.be/ldZSyfvg7tY">https://youtu.be/ldZSyfvg7tY</a> . From the feedback form, all of the people who responded rated the talk 'good' and 'excellent' and one person said that was the talk they liked most about the whole event!

TABLE 4 DiSCOVERY communications, outputs and dissemination log (continued)

Year 1				2021–2
When	Format	Title	Who	Audience/outputs
7 November 2023	Article	WP2 protocol	Linda Birt	Citation: <sup>15</sup> <a href="#">Table 1</a>
28 November 2023	Talk	DiSCOVERY study	Juniper West Corinna Hackmann	NSFT Recovery College 10 year anniversary event (in-person) The Space, Rowntree Way, Norwich
20 December 2023	News	DiSCOVERY newsletter (3)	Maria Sanchez	Study newsletter third edition sent to stakeholder groups and interested parties
Year 3				2024
When	Format	Title	Researcher/s	Audience/outputs
7 March 2024	Talk	DiSCOVERY and SPLENDID studies	Chris Fox Juniper West	NHS Norfolk and Waveney Integrated Care Board (ICB) Dementia Working Group meeting
27 March 2024	News	DiSCOVERY newsletter (4)	Jarin Alam	Study newsletter fourth edition sent to stakeholder groups and interested parties
13 May 2024	Article	WP1b realist review	Melanie Handley	Citation: <sup>17</sup> <a href="#">Table 1</a>
18 September 2024	Talk	DiSCOVERY study findings	Chris Fox Juniper West	Alzheimer's Society Norfolk and Suffolk Dementia Conference at the Kings Centre, Norwich: 'My Diagnosis, My Future'. Mixed public and healthcare professional audience > 150 delegates
8 October 2024	Talk	Brief follow up with some DiSCOVERY study insights	Juniper West Rachael Litherland Allison Batchelor Martyn Gardener	MSNAP 15th Annual Forum (online). Annual Forum recording
29 October 2024	Discussion	DiSCOVERY study dissemination planning	Chris Fox Juniper West Tom Rhodes	With Bronte Heath and colleagues from the Alzheimer's Society Research Evidence team
4 November 2024	Symposium	Understanding outcomes for people with dementia who deliver or attend Recovery College dementia courses	Linda Birt	ARC East Midlands event; <a href="https://arc-em.nihr.ac.uk/news/regional-dementia-care-research-symposium-highlights-underserved-communities">https://arc-em.nihr.ac.uk/news/regional-dementia-care-research-symposium-highlights-underserved-communities</a>
28 November 2024	Talk	Understanding outcomes for people with dementia who deliver or attend Recovery College dementia courses	Linda Birt Juniper West Martyn Gardener	Dementia Open Forum (online) hosted by University of East Anglia
10 December 2024	Study partners meeting	Understanding outcomes for people with dementia who deliver or attend Recovery College dementia courses	Juniper West Linda Birt Jarin Alam Bonnie Teague Tom Rhodes	Final meeting with Partners in Research and Staff advisory groups, staff and peer tutors from case study sites, researchers and Steering Committee Chair to give feedback on guidance resources outputs
Year 4 Post study				2025
When	Format	Title	Researcher/s	Audience/outputs
31 January 2025	Talk	Understanding outcomes for people with dementia who deliver or attend Recovery College dementia courses	Linda Birt Rachael Litherland Allison Batchelor	ImROC hosted Recovery Colleges Learning Set

continued

TABLE 4 DiSCOVERY communications, outputs and dissemination log (continued)

Year 1				2021-2
When	Format	Title	Who	Audience/outputs
21 February 2025	Article	WP2 results paper 1	Linda Birt	Citation: <sup>19</sup> <a href="#">Table 1</a>
11 March 2025	Article	WP3 scoping review	Jarin Alam	Citation: <sup>18</sup> <a href="#">Table 1</a>
21 March 2025	Article	WP2 results paper 2	Linda Birt	Citation: <sup>57</sup> <a href="#">Table 1</a>
Planned				2025
When	Format	Title	Researcher/s	Audience/outputs
June 2025	Poster	Providing post-diagnostic dementia support through Recovery Colleges: a realist evaluation of what works for who, why, and when	Linda Birt on behalf of the DiSCOVERY study team	British Society of Gerontology
10 July 2025	Poster	Best practice in post-diagnosis care for people with dementia through Recovery Colleges (DiSCOVERY-Post-diagnostic Dementia Support within the ReCOVERY College Model)	Chris Fox Juniper West Geoff Wong Emma Wolverson Fiona Poland Melanie Handley Linda Birt Esme Moniz-Cook Corrina Hackmann Bonne Teague	Alzheimer's Association International Conference (AAIC) <sup>®</sup> Toronto Canada
	Article	WP2 results paper 1	Linda Birt	To be resubmitted
	Article	PPIE Partners in Research	Rachael Litherland	For submission