



HEALTH &
SOCIAL CARE
PARTNERS



UNIVERSITY OF
OXFORD



Innovations
in Dementia



Applied Research Collaboration
East of England

STUDY PROTOCOL

FULL/LONG TITLE OF THE STUDY

**Post-Diagnostic Dementia Support within the ReCOVERY College Model:
A Realist Evaluation**

SHORT TITLE **DiSCOVERY**

WORK PACKAGE 1 • Months 0 - 6

**Building an initial understanding of Recovery College dementia
courses in the NHS**

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SIGNATURE PAGE

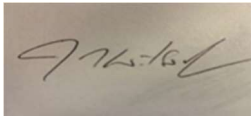
The undersigned confirm that the following protocol has been agreed and accepted and that the Co-Chief Investigators agree to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

We agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

We also confirm that we will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature:



Date: 06.12.2021

Name (please print): DR JONATHAN WILSON

Position: Research Director

Co-Chief Investigator:

Signature:



Date: 06.12.2021

Name: (please print): PROFESSOR GEORGE CHRISTOPHER FOX

Co-Chief Investigator:

Signature:



Date: 06.12.2021

Name: (please print): MS JUNIPER WEST

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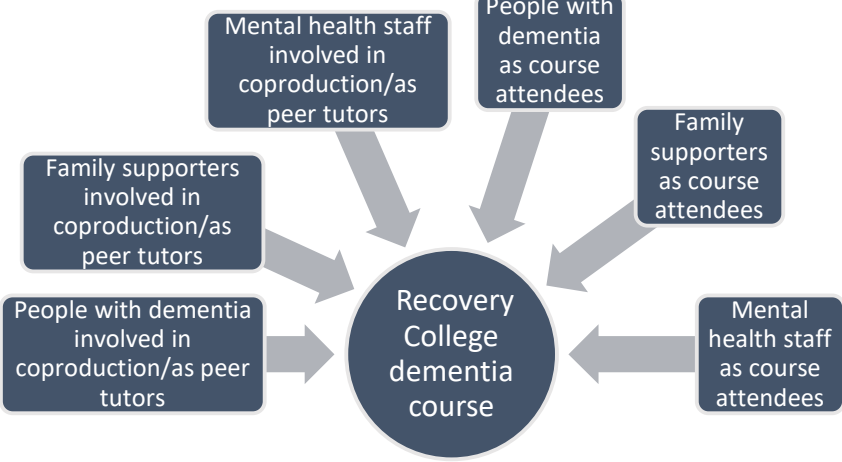
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KEY STUDY CONTACTS, PROTOCOL CONTRIBUTORS & ROLES

<p>Co-Chief Investigator Overall study lead responsible for project delivery; mentor for JW's co-leadership role throughout all WPs integrating diverse aspects of the research, leading study project management/steering groups, managing/supervising the appointed Study Manager/research assistant psychologist/other research staff, and co-leading WP3.</p>	<p>Professor George Christopher Fox (CF) ORCID ID: 0000-0001-9480-5704 Professor of Clinical Psychiatry, University of Exeter/Consultant Psychiatrist, Memory Services, North Norfolk & Norwich Care Group, Norfolk and Suffolk NHS Foundation Trust Room 2.05, South Cloisters, St Luke's Campus Heavitree Road, Exeter Devon, EX1 2LU christopher.fox@exeter.ac.uk 01392 722 043 PA Katie Briggs K.Briggs@exeter.ac.uk 01392 722 043</p>
<p>Co-Chief Investigator Joint responsibility mentored and supervised by CF for the aspects of project delivery for all WPs as detailed above, co-researcher with LB for WP2.</p>	<p>Ms Juniper West (JW) ORCID ID: 000-0003-0802-7243 Research Development Lead, Older People's Services S14 Norfolk and Suffolk NHS Foundation Trust St Andrews Lodge, Julian Hospital Bowthorpe Road Norwich, Norfolk, NR2 3TD juni.west@nsft.nhs.uk 07500 816 931</p>
<p>Study Manager</p>	<p>Mr Thomas Rhodes (TR) Senior Research Facilitator Norfolk and Suffolk NHS Foundation Trust The Knowledge Centre, Hellesdon Hospital Drayton High Road Norwich, Norfolk, NR6 5BE tom.rhodes@nsft.nhs.uk 01603 421 552</p>
<p>Lead/Sponsor Contact</p>	<p>Dr Jonathan Wilson Research Director Norfolk and Suffolk NHS Foundation Trust The Knowledge Centre, Hellesdon Hospital Drayton High Road Norwich, Norfolk, NR6 5BE jon.wilson@nsft.nhs.uk</p>
<p>Funder/Contact</p>	<p>Alessandra Wilkinson-Smith NETSCC Monitoring Team National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre University of Southampton Alpha House, Enterprise Road Southampton SO16 7NS netpostawardsetup@nihr.ac.uk 02380 594 378</p>
<p>Key Protocol Contributors & Roles Lead for PPI, qualitative methodology and ethnography for WP2 and supporting WP4.</p> <p>Expertise in qualitative methodology and ethnography, WP2 co-researcher with JW, expertise in PPI and co-production leading WP4.</p>	<p>Professor Fiona Poland (FP) Professor of Social Research Methodology University of East Anglia School of Health Sciences f.poland@uea.ac.uk PA Pel Fordham p.fordham@uea.ac.uk</p> <p>Dr Linda Birt (LB) Senior Research Associate University of East Anglia School of Health Sciences</p>

<p>Work Package 1 Co-Lead Expertise in realist evaluation, co-lead realist review and evaluation with GW all WPs.</p> <p>Work Package 1 Co-Lead Experienced realist methodologist, co-lead realist review and evaluation with MH all WPs.</p> <p>Experienced/expert librarian/realist reviewer, rapid realist review WP1.</p> <p>Lead in applied psychosocial approaches to dementia, WP1a. co-lead with EW, WP3 co-lead with CF/JW and EW.</p> <p>Expertise in stakeholder collaboration and qualitative methods, WP1a co-lead with EM-C, WP3 co-lead with CF/JW and EM-C.</p> <p>Input across all WPs for areas relating to strategic recruitment and engagement protocols to ensure inclusive participation of underserved groups for PPI, case study sites and participants.</p> <p>Expertise with ImROC, Recovery College research and evaluations, outcome measures, realist methodology and co-production; supporting WPs 1, 2 and 4.</p> <p>Expertise in co-production/ implementation of Recovery College dementia/post-diagnostic service, WP1, WP3 and WP4 support.</p> <p>Expertise in acceptability of interventions, clinical memory, and post-diagnostic services, WP3 and WP4 support.</p> <p>PPI co-lead, National dementia PPI stakeholder engagement and PPI advisory group day-to-day project manager across all WPs</p>	<p>linda.birt@uea.ac.uk</p> <p>Dr Melanie Handley (MH) Senior Research Fellow, Health and Care for Older People University of Hertfordshire Centre for Research in Public Health & Community Care (CRIPACC) m.j.handley@herts.ac.uk</p> <p>Professor Geoffrey Wong (GW) Associate Professor in Primary Care University of Oxford Nuffield Department of Primary Care Health Sciences Medical Sciences Division geoffrey.wong@phc.ox.ac.uk</p> <p>Claire Duddy (CD) Expert librarian, realist methods University of Oxford Nuffield Department of Population Health claire.duddy@phc.ox.ac.uk</p> <p>Professor Esme Moniz-Cook (EM-C) Professor of Psychology Ageing & Dementia Care Research University of Hull Faculty of Health Sciences E.D.Moniz-Cook@hull.ac.uk</p> <p>Dr Emma Wolverson (EW) Senior Lecturer Ageing and Dementia/Clinical Psychologist University of Hull Faculty of Health Sciences E.Wolverson@hull.ac.uk</p> <p>Dr Bonnie Teague (BT) Head of Research Norfolk & Suffolk NHS Foundation Trust NSFT Research bonnie.teague@nsft.nhs.uk</p> <p>Dr Corinna Hackmann (CH) Research Development Lead, Adult, Recovery and Well-Being Services Norfolk & Suffolk NHS Foundation Trust corinna.hackmann@nsft.nhs.uk</p> <p>Ms Ruth Mills (RM) Consultant Clinical Psychologist Norfolk & Suffolk NHS Foundation Trust East Suffolk Care Group, Older People's Services ruth.mills@nsft.nhs.uk</p> <p>Dr Kathryn Sams (KS) Specialised Clinical Psychologist Norfolk & Suffolk NHS Foundation Trust West & South Norfolk Care Group, Older People's Services kathryn.sams@nsft.nhs.uk</p> <p>Ms Rachael Litherland Director Innovations in Dementia CIC rachael@myid.org.uk</p>
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STUDY SUMMARY - WORK PACKAGE 1

Study Title	Post-Diagnostic Dementia Support within the Re COVERY College Model: A Realist Evaluation (DiSCOVERY) Work Package 1 - Building an initial understanding of Recovery College dementia courses in the NHS
Study Design	Developing an initial realist programme theory incorporating data from national survey/s, a rapid realist review and stakeholder engagement.
Stakeholder Engagement Participants	
Study Participants	Two stakeholder advisory groups will include PPI advisors and staff working in NHS mental health service provided memory services and/or co-producing Recovery College dementia courses, and who will be recruited via Innovations in Dementia and the UK surveys. Survey participants will include NHS Recovery College managers/ staff and staff working in NHS Memory Services.
Planned Sample Size	For the survey/s of Recovery Colleges and memory services we aim for up to 70 responses - a response rate of 50% from Recovery Colleges and mental health organisations from across the UK. A low uptake will not have statistical consequences relating to the progress of the study, but will only impact generalisability of our understanding of Recovery College dementia course provision.
Follow-up	n/a
Study Period	6 Months
Research Question/Aim(s)	<p>Research question: What factors support the co-production and successful delivery of Recovery College dementia courses: what works, for whom and in what circumstances?</p> <p>Aims This study aims 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 families/supporters and staff.</p> <p>Objectives for Work Package 1</p> <ol style="list-style-type: none"> 1 To map the provision of Recovery College dementia courses across the UK. 2 To conduct a rapid realist review of evidence from peer-reviewed and grey literature, related theory, policy/practice guidance and key stakeholders, to specify what components characterise a recovery-focused approach to adjusting to a diagnosis and to providing appropriate post-diagnostic support in dementia. 3 To identify the key components of effective Recovery College dementia courses in an evidence-based, realist programme theory.

KEY WORDS: dementia, post-diagnostic support, recovery, co-production, peer support, realist review

FUNDING

FUNDER	FINANCIAL SUPPORT GIVEN
National Institute for Health Research (NIHR) Health Services & Delivery Research (HS&DR)	£601,757.29

ROLE OF STUDY SPONSOR

Norfolk and Suffolk NHS Foundation Trust (NSFT) is the study sponsor. Responsibility for all aspects of study design, initiation and management, conduct, data analysis and interpretation, manuscript writing, and dissemination of results will be delegated to the Co-Chief Investigators (Co-ClIs). The sponsor controls the final decision regarding any of these aspects of the study.

ROLES & RESPONSIBILITIES: STUDY MANAGEMENT COMMITTEES, GROUPS & INDIVIDUALS

Two main groups will be convened to oversee the coordination and conduct of the whole study and ensure participant safety and well-being.

1 Study Steering Committee (SSC) The SSC will meet remotely twice per year for each year of the project - x 6 meetings in total at key milestone points. It will be chaired by an independent expert and will have majority (75%) independent representation. Senior members of the research team will meet with the SSC who will oversee the management of the study and ensure scientific integrity, reporting regularly to NSFT. Honoraria is included in the grant for independent SSC members. SSC Terms of Reference can be found in Appendix 1.

2 Project Management Group (PMG) The study will be delivered across four work packages over 36 months (01 Jan 2022 to 31 Dec 2024). NSFT will set up collaborative agreements between all partner organisations to detail each partner's specific responsibilities and role. A PMG co-chaired by Co-ClIs Chris Fox and Juniper West will be responsible for overseeing reports and high-level monitoring delivery against study objectives. Chris Fox will mentor and supervise Juniper West in her academic leadership role. The PMG will meet monthly with research team members and PPI advisors identified and independently supported by Rachael Litherland to ensure effective project management across all sites and that key work package milestones are met. Two realist research co-leads Melanie Handley and Geoffrey Wong, who are experienced realist methodologists, will oversee the rapid realist review and evaluation. The study is supported by NSFT research delivery policies available at <https://www.nsft.nhs.uk/research-compliance-and-policies>. Dr Jon Wilson, Research Director at NSFT is sponsor representative, responsible for overall oversight/project management, financial reporting, and adherence to Trust and national ethical and quality policies. The PMG's activities will be supported by Study Manager Tom Rhodes (0.4WTE), and the research assistant psychologist (1.0WTE) (TBA) who are responsible for day-to-day activity coordination. This group will be responsible for writing and submitting NIHR progress reports, ethics reports and amendment approvals.

Working with two stakeholder advisory groups We are going to get help from our stakeholders to co-produce and later refine our initial programme theory during the course of the project. The stakeholder groups will be involved in a two-way engagement process progressing decision-making, which is important given the iterative nature of our study design and evolving findings. Stakeholder recruitment will encompass participant selection aimed at including diversity of members in the groups. NSFT has developed a comprehensive departmental Equality, Diversity and Inclusion (EDI) strategy for the study which will inform user involvement activities, questions for the Work Package 1 surveys, selection of Recovery College sites, stakeholder participants and dissemination. The strategy also includes information about routine data collection of specific demographic and socioeconomic characteristics relevant to each work package. The full EDI strategy can be found in Appendix 2.

1 Patient & Public Involvement (PPI) Stakeholder Advisory Group (a group name will be devised together with the group) The overall lead for PPI is Fiona Poland. The study PPI advisory group is being recruited to and facilitated independently by Rachael Litherland from Innovations in Dementia - who host the national Dementia Engagement and Empowerment Project (DEEP - <https://www.dementiavoices.org.uk>). DEEP is a UK wide network of over 85 involvement groups of people with dementia. Rachael Litherland and members of the research team, who have extensive experience of working with people with dementia in PPI roles within research, will share good practice examples from existing PPI work with the advisory group. The group will be central to all the research activities, working alongside all work packages. Members will include both people with dementia who have experience of co-producing a Recovery College dementia course, and people with dementia who have attended a course from across the UK. The group will include people with lived experience and their family/friend supporters who have helped to shape the research; Mrs Pauline Bunker, Mr Irvin Bunker, Mr Peter Berry, Mrs Teresa Berry and Ms Deb Bunt. For all, the membership will be rolling, with new members being able to join the group if other people no longer feel able to participate. However, a key focus of Rachael Litherland's role is providing the support to people to continue their involvement even as people's needs change. Due to the COVID-19 pandemic it is anticipated that the group will meet using the Zoom online video platform, but would aim to meet face-to-face at least once a year in different parts of the country if current COVID-19 restrictions allow. The group will work together to create their own strong group identity, and Rachael Litherland will support the group to help them prepare for their work - including making documents and approaches dementia accessible and encouraging the research team to adapt their writing and language. Rachael Litherland will help to facilitate productive and enjoyable meetings, and ensure adequate de-briefing after meetings for people with dementia and their supporters. These will help the research team to involve people with dementia and their supporters in the best ways possible, as they will learn with and from group members. Where we want to include a wider range of perspectives on the study from people with dementia, we will connect to people via DEEP where the group will be central in communications and interactions with the DEEP network. Rachael Litherland will support the group to be proud of their work, and will work with the research team to ensure the group are central to the running of the project.

2 Staff Stakeholder Advisory Group (SSAG) This group will be recruited to and facilitated by Melanie Handley, Linda Birt, Juniper West, Ruth Mills and Kathryn Sams. The staff group will be psychiatrists (n=3-5), community mental health nurses including independent nurse prescribers (n=3-5), clinical psychologists (n=3-5), occupational therapists (n=3-5), social workers (n=3-5) and assistant practitioners/community support workers (n=3-5) working in NHS mental health service provided memory services and/or co-producing Recovery College dementia courses, and who will be recruited via the WP1a survey.

PLAIN ENGLISH SUMMARY OF RESEARCH

What is the problem?

Receiving a diagnosis of dementia is life-changing for the person and their family. Stigma can make adjusting to the diagnosis frightening and isolating. Where people live, the type of dementia they have, or lack of opportunities to meet peers, can all affect the quality of support post-diagnosis.

Mental health trusts have adopted Recovery Colleges as a way of supporting adults with a range of difficulties. These offer educational courses for people who use mental health services, their families and staff. People living with mental health difficulties help with the design and running of the courses. There are also staff members called peer tutors.

It may seem puzzling to talk about 'recovery' in dementia if dementia is a progressive illness. However, recovery in mental health refers to 'recovering a life after diagnosis'. This 'recovery' is about managing difficult symptoms whilst living a meaningful, enjoyable life. Some Recovery Colleges across England offer courses with/for people with dementia.

What do we want to find out?

We want to understand how, following diagnosis of dementia, support within Recovery Colleges can help people. We want to find out what attending courses is like for people with dementia, their families and staff. How do they find co-designing and co-running ('co-produce') courses? We also want to know how people who access NHS memory services find out about Recovery College dementia courses. Do these courses have interest and relevance following a dementia diagnosis, for whom and when?

How will we do this?

We will ask questions to find out what works for whom, in what circumstances, and why. We will start from our early ideas on what makes a Recovery College dementia course work for people who take part.

We will visit different Recovery College dementia courses around England and interview people with dementia, their families and staff. We will discuss this information with everyone involved then, use it, to reflect real life. We will use this updated theory to co-produce guidance, learning and organise resources for UK Recovery Colleges. We can then adapt this to suit local dementia courses. We will involve people with dementia, their families and staff in creating these resources.

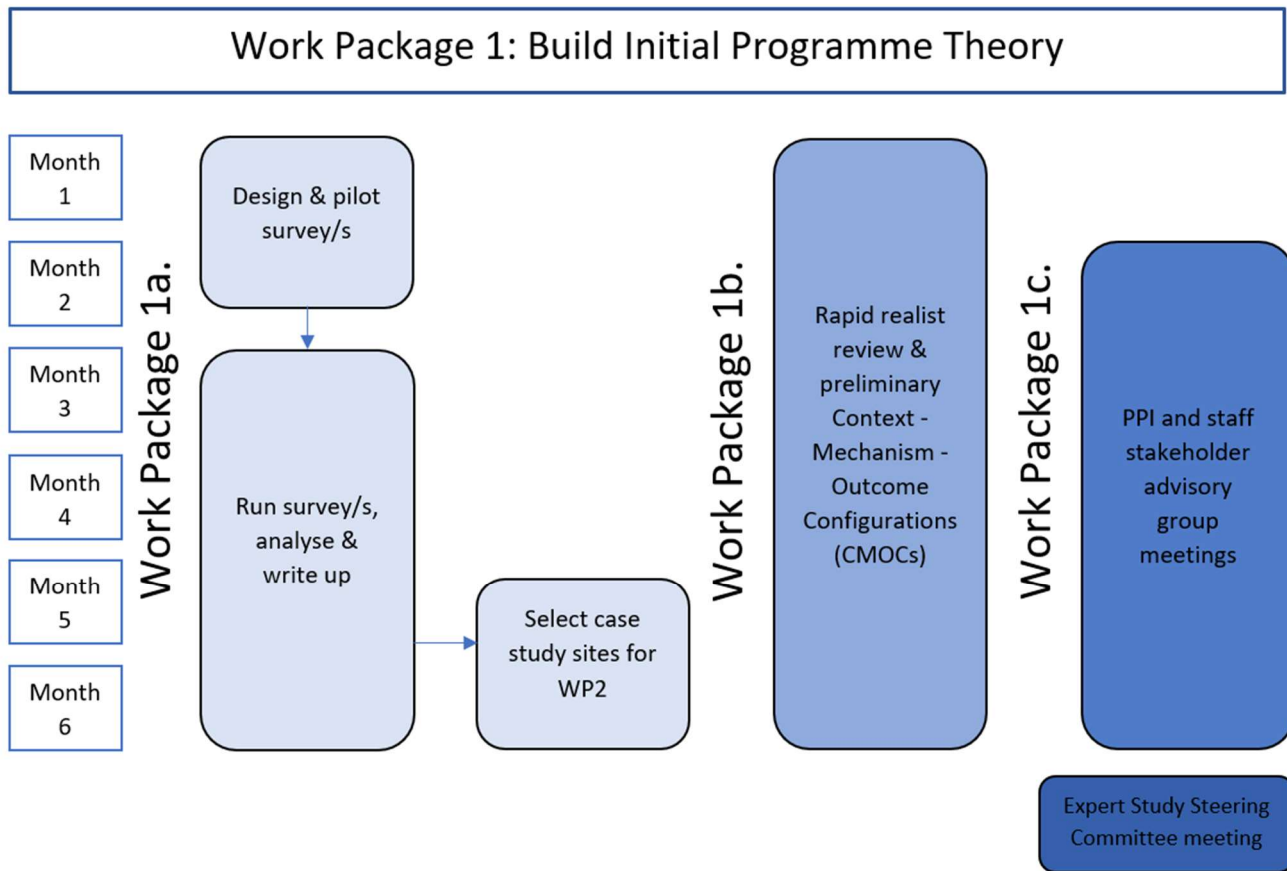
How have we worked with people with dementia?

People with dementia and their families helped shape our starting theory of how Recovery College dementia courses could work, by sharing their experiences of what has and hasn't helped and what is important. We will share our findings and resources through services, groups that support people with dementia and the public.

How will we share our findings?

We will work together with the national Dementia Engagement and Empowerment Project (DEEP). We will share our findings and co-produced resources through local and national groups. These will include NHS memory services, UK Recovery College and other groups that support people with dementia. We will use a variety of media including podcasts, films and talks to engage the public.

STUDY FLOW CHART WORK PACKAGE 1



Illustrative timeline and research leads/team + for WP1 activities

Task/Month	Leads/Team	Year 1					
		Mth 1	Mth 2	Mth 3	Mth 4	Mth 5	Mth 6
WP1 build initial programme theory	Melanie Handley/Geoffrey Wong						
WP1a. Recruit to/form PPI advisory group	RL						
WP1a. Design, pilot survey	EW/EM-C/BT/LB/CF/JW/RM/KS						
WP1a. Run survey, analyse, write-up	EW/EM-C/JW/BT						
WP1a. Recruit to/form staff advisory group	JW						
WP1a. Select case study sites WP2	BT/LB/JW						
WP1b. Rapid realist review/prelim. CMOCs	MH/GW/CD/CH/CF/JW/EM-C						
WP1c. Stakeholder advisory group meetings	MH/LB/RL/JW/RM/KS						
Study Steering Committee meeting							

Section 1. BACKGROUND

Dementia and coping with a diagnosis of dementia

Estimates suggest that by 2040, 1.6 million people will be living with dementia in the UK.¹ This will include an estimated 50,000 people living with dementia from ethnic minority groups by 2026, a figure rising much more rapidly than in the general population.² Receiving and adjusting to a diagnosis of dementia is life-changing for the person and their family, bringing many uncertainties compounded by social stigma.³ Two Patient and Public Involvement (PPI) advisors for this project from a local group of people living with dementia and their respective family supporters - reported feeling unable to disclose their diagnosis to others, worsened by negative attitudes in society about dementia and ageing.³ 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 living with dementia becoming disempowered, silenced and marginalised.⁴ 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.⁵

The post-diagnosis period is critical to support adjustments to individual needs as they change,⁶ where people living with dementia and if applicable, their family supporters should be offered flexible access to a range of specialist support. Most people are assessed and diagnosed within secondary mental health memory services and after their diagnosis should be offered support tailored to meet their individual specific needs.^{7,8} Many people do receive this, however there is significant variability in the quality, duration and eligibility for post-diagnostic support in dementia across the UK, and what there is generally remains poorly defined or evidenced.⁹⁻¹¹ This is problematic because people are often discharged from mental health services having received a diagnosis, but without access to ongoing support to manage the social-psychological demands. Additionally, unintentional messaging focused around cognitive deficits cause distress, for example stopping driving and arranging powers of attorney leads to diagnostic services inadvertently prescribing people 'giving up life as they know it', defined as 'Prescribed Disengagement™'.^{12,13}

Experiencing this can reinforce feelings of isolation and loss and undermine engagement of people living with dementia and their family finding ways to 'live well' with dementia. PPI advisors told us their experiences was of families left unsupported to find what the person with lived experience might need, and self-navigating access to primary and charitable sector services without knowledge of likely immediate or long-term needs. This experience is supported by research which has found psychiatrists feeling limited in their ability to discuss wellbeing and living well with people they were diagnosing with dementia because of the lack of services available to offer this kind of support.¹⁴ Similarly, a survey of dementia care coordinators found that they saw offering post-diagnostic services to ethnic minority people with dementia was 'challenging', with little provision to mitigate language or cultural barriers,¹⁵ and a recent study found that ethnic minority groups were less likely than white British groups to be offered or use post-diagnostic community support for dementia.¹⁶ Therefore, secondary mental health and primary care services vary widely in how post-diagnostic support is explained and provided¹⁷ and what should be offered, to whom and when. With many people ineligible for medication treatment and being discharged without specialist follow up, it is likely that diagnosis without adequate post-diagnostic support will not benefit or may actually be harmful. Early discharge reports suggest opportunities are missed to support positive adaptation, risking people and their families adopting maladaptive coping strategies such as substance misuse and self-neglect, and generating additional later mental health issues and care costs.^{11,18,19}

Peer Support within Mental Health Recovery Colleges

Existing NHS mental health post-diagnostic support services - described throughout this protocol as memory services - could address individuals' unmet needs by drawing on the lived experience of people living with dementia and equally those of their families/friend supporters. This could specify and contextualise the unmet needs, to improve post-diagnostic support outcomes by increasing participation of people living with dementia and their family supporters in co-production and peer support.³ This approach is already 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/>. A 'recovery-focused', peer-support, adult learning approach is adopted and embedded within a strategic care delivery approach in mental health Trusts, 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.²⁰ Five key linked conceptual processes (the **CHIME** recovery 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 **empowering** control over life and a focus on strengths.²¹ Working with mental health Trusts, ImROC founded Recovery Colleges which have rapidly become a core part of recovery-focused mental health services. As of 2017, there were 85 Recovery Colleges in the UK (77 in England, 2 in Scotland, 5 in Northern Ireland and 1 in Wales).²²

A typical adult mental health Recovery College offers courses on mental health and recovery, designed to increase attendees' knowledge, skills and confidence in self-management of their own mental health and wellbeing. Courses range from one-off sessions to several sessions spread over a set number of weeks. All courses are co-produced and co-delivered (i.e. co-taught) by peer tutors - that is, people with lived/expert experience - and mental health staff, who also enrol on courses as attendees. Peer tutors prepare for their role through having training to teach and support, and receive supervision to ensure any sensitive issues can be supported effectively. All people attending Recovery Colleges together are equally considered as 'students', not patients or service users or staff. Since the onset of the COVID-19 pandemic, many Recovery Colleges have delivered content remotely via online video platforms such as Zoom. Unlike other areas of mental health service provision (e.g. therapeutic groups), attendees are not referred by mental health staff. Instead, course prospectuses, which will differ from college to college, are advertised in printed brochures and on Trust websites. Dedicated Recovery College staff help people to *connect* with peers, develop individual learning plans and support enrolment on courses to address individual mental health 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 and recovery principles of co-production in involving and *empowering* people with lived experience and peer support in all aspects of course design and delivery.²⁰

In addition to helping people with mental health difficulties build meaningful, satisfying lives, Recovery Colleges also 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 co-production. Even before the COVID-19 pandemic, mental health staff reported high stress as service demand far exceeded resources, feeling unable to ameliorate patients' emotional distress and so being disempowered.²³ The Francis Inquiry²⁴ highlighted professional disengagement, whereby clinicians are not placed at the fore to promote change, which can lead to accepting poor standards of care. In contrast, staff involved with Recovery Colleges report renewed motivation and positive impact on how they view the organisation,²⁵ greater capacity to see strengths and potential, developing positive attitudes to recovery and new skills to support patients' self-management.^{26,27} Staff note the inspiring role of peer tutors within Recovery Colleges and the

novel perspectives individuals bring through knowledge of lived experiences.²⁵ Importantly, this creates possibilities for changing attitudes, challenging “them and us” culture and tackling stigma and discrimination in the mental health system and beyond.^{25,27}

Section 2. EVIDENCE REVIEW

Recovery Colleges for people with dementia

There is extremely limited published information on UK Recovery Colleges adopting a recovery approach for people living with dementia. Initial searches were conducted in 2019 across the Embase, PsycINFO, CINAHL and MEDLINE healthcare databases, using combinations of the search terms ‘recovery’, ‘recovery college*’, ‘intervention*’, ‘dementia*’ and ‘alzheimer*’, returning 59 results. Only one of these described processes and possible benefits of dementia courses from one Recovery College (conference poster)³⁵ which reported on recovery principles use in Lincolnshire Recovery Colleges. These suggested a recovery approach could help reduce demand for services, whilst helping raise the quality of life of people with dementia. One other article from a different Recovery College³⁶, a Faculty of Psychology for Older People newsletter, described co-producing a dementia course for the Devon Recovery Learning Community. This concluded that “*recovery orientated practice and co-production can and does work in the context of dementia*” (2017:24).

We re-ran the search in March 2021 finding no new results except for our published UK scoping survey. Our early scoping survey for this project aimed to find out if and how many other UK Recovery Colleges are/were offering dementia courses, how these dementia courses were developed and delivered, and who can/could attend.²⁹ The survey was emailed to all Recovery Colleges in the UK. Of the 28 Recovery Colleges who responded, (32.5%), 11 (39.3%) reported they were currently offering dementia courses, whilst 17 (60.7%) were not. Of those 17 not currently running courses, 3 had previously run dementia courses and planned to do so again; 2 had previously run courses but did not have plans to do so again; 5 had never run dementia courses but had plans to start; 6 had never run dementia courses and did not have plans to do so and one response was incomplete. Seven responders expressed interest in remaining involved in our proposed research and left their contact details. Recent updates on the impact of the COVID-19 pandemic on the running of dementia courses in Recovery Colleges illustrates a mixed response. Some Recovery Colleges reported running dementia courses exclusively online at present, with a view of offering a blended approach of both online and face-to-face courses when possible. Others reported that dementia courses are currently on hold until face-to-face meetings can resume. Further recent findings include a service evaluation in the lead organisation Norfolk and Suffolk NHS Foundation Trust (NSFT) exploring experiences of co-producing a Recovery College dementia course, from interviewing a person living with dementia (aged mid-80s), their family supporter and two staff. A thematic analysis identified three analysis domains: *positive feelings of co-production*; the impact of collectively creating a *powerful experienced-based learning environment*, and each individual finding the co-production experience and meeting others on the course to be *helping, confronting dementia together*.³⁷ Given the limited specific evidence, we have also referred to more general evidence for post-diagnostic support in dementia and from Recovery Colleges in the context of adult mental health services.

Post-diagnostic support for people with dementia

While support groups and initiatives have developed to address post-diagnostic support, reviews of post-diagnostic support services for people living with dementia highlight that despite much activity for post-diagnostic support, its evidence base is limited⁶ with few evidence-based social-psychological interventions for people living with dementia in the community.⁶ Neither did we find any research on the impact of socioeconomic factors including deprivation, on post-diagnostic dementia support.

Recovery Colleges in the context of adult mental health

No controlled trials have explored Recovery Colleges' effectiveness, however evidence is emerging about their impact. ImROC have synthesised evidence for Recovery College components²⁰ identifying course co-production as a key defining feature.²⁶ Recovery Colleges create adult learning environments which moderate power dynamics between service users and staff, to reduce stigma and increase attendees' sense of hope and empowerment.^{25,27,38} Attendees report developing novel coping strategies, improving self-worth, wellbeing and quality of life.³⁸⁻⁴¹ These findings are highly relevant for helping people living with dementia adjusting to diagnosis with more hope for a meaningful life alongside the progressive symptoms, and challenge attitudes and systems by co-producing fresh understandings of the meaning of recovery.²⁵ Recovery College courses offer access to distinctive peer support both from co-producing courses and/or attending them.²⁵ A national strategy to promote dementia peer support through developing learning networks also aims to empower people living with dementia to make choices in planning for the future.³¹ A theory of change model for Recovery Colleges has been co-developed within adult mental health contexts that identifies four mechanisms of change⁴²: empowering environment - opportunities for choices; shifting balance of power; enabling different relationships and connecting with peers; and facilitating personal growth through shared learning and strength-building. Outcomes were changes in the attendee including improved wellbeing, reinforced by life changes they could observe. This model is highly applicable to enabling desired outcomes for post-diagnostic support in dementia - refer to the Theory of Change map in Appendix 4.

Linking with ongoing Recovery College research - RECOLLECT2 and sustainability

Ongoing research examines Recovery Colleges through the Recovery Colleges Characterisation and Testing (RECOLLECT) programme.⁴³ The RECOLLECT2 project (NIHR200605) aims to identify what is not known about Recovery Colleges' effectiveness and how their organisation benefits users of adult mental health services. The RECOLLECT2 study team are examining these to see what factors affect costs, student outcomes and fidelity measures in what types of Recovery College, by surveying 77 Recovery College managers nationally, informing selection of diverse sites for qualitative case studies. Qualitative interviews with managers, peer/staff tutors and students at 6 Colleges are used to identify how each College is organised and how participants think this might influence its effectiveness. Student outcomes and service use across 25 Recovery Colleges will be measured when they register, then at 4, 8 and 12 months. Findings will be compared with matched controls (users of mental health services who do not access Recovery Colleges).

An integral difference between RECOLLECT2 and this project is our focus on exploring the experiences of the impacts of the cognitive impairments associated with dementia, such as difficulties with memory, or changes in language and social interactions, and how the Recovery College model adapts to meet the needs of people with dementia, both as peer tutors and as attendees. For this reason, the results of RECOLLECT2 may not be valid for this population, particularly as a key focus of RECOLLECT2 involves assessing Recovery Colleges' fidelity to the recovery model. In addition, many of the main outcomes being looked at by RECOLLECT2, such as student outcomes and service use, would not be appropriate for this project. We greatly value the support and expertise of RECOLLECT2's Co-Chief Investigator Professor Mike Slade as a link between the two projects. The overall aim of assessing aspects of Recovery College courses that make them more effective is shared, and learning from each stage of both projects can be taken forward by the other in order to get the most out of each stage. DiSCOVERY complements RECOLLECT2 in that the latter assesses the effectiveness of Recovery College courses, whilst the former seeks to explain why, when and for whom effectiveness is likely to occur. This is because adult mental health courses and dementia courses are likely to differ markedly, for instance, in how each type of Recovery College is organised to support specific needs of people living with cognitive impairment, what information may be made accessible to them and the role of

family/friend supporters and, specifically, what factors support the co-production and successful delivery of Recovery College dementia courses.

The negative impact of COVID-19-related restrictions on people living with dementia and their families/supporters quality of life, mental health and functioning means research investigating support for people with dementia to 'live well' remains a high priority for research funders. There is sustained and growing interest in policy for recovery-focused mental health services. The first UK Recovery College was set up in 2009, growing to 85 by 2017.²² The model has been replicated internationally²⁰ with Recovery Colleges now in existence or developing in 22 countries.⁴⁴ Despite this exponential growth, published evidence of impact/effectiveness of Recovery Colleges is limited to case studies and local evaluations.³⁸⁻⁴¹ Although RECOLLECT2 is on-going and exploring cost-effectiveness of Recovery Colleges in England, the evidence-base, theory of implementation and impact of co-producing and attending Recovery College dementia courses is largely unknown to people living with dementia, their family supporters and mental health staff. With 19 out of the 28 UK Recovery Colleges responding to our scoping survey positively engaging with or planning to engage with the topic of dementia, there is therefore an important and recognised gap in empirical evidence, in best practice guidance and in knowing which meaningful outcome domains may be measurable, to enable impact on living well with dementia to be subsequently evaluated for an approach being implemented on this scale.⁴²

Both the changing narrative around dementia care moving from promoting negative stereotypes to 'living well' with dementia³, and the potential to align the theoretical frameworks of CHIME and person-centred care, suggests Recovery Colleges may well offer a novel, flexible and effective option for peer-led post-diagnostic support in dementia. Recovery Colleges are growing in number, despite limited knowledge of their key components or how to best deliver them, and they are already being delivered within the NHS and therefore available to research. Exploring sustainability and on-going funding of the recovery college model is beyond scope of our study, but after discussing the issue with several senior/national colleagues who are involved in Recovery College delivery, there is nothing to currently suggest that Recovery College funding is vulnerable to funding or commissioning cuts, and if anything, it is seen as a sustainable model of service delivery which is expanding. Of relevance to our plans for dissemination, the sixth edition of the MSNAP standards⁸ has been mapped against sustainability principles developed by the Royal College of Psychiatrists Sustainability Committee, highlighting a recovery-focused self-management approach as an important part of mental health service sustainability. In addition to linking with MSNAP, as part of our dissemination plan, we will share our study progress and findings with service commissioners and Integrated Care System leaders. The next step in evidencing in-depth understanding of the contexts, mechanisms and outcomes of dementia courses in Recovery Colleges is needed for us to ascertain what is the distinctive and relevant ingredient in post-diagnostic support in dementia that is generated and supported through Recovery Colleges. This research will apply the theoretical models of CHIME and person-centred care to provide clear conclusions for rebalancing information exchange and shared decision-making within dementia diagnostic processes. This will enable people with dementia and their family/friend supporters - if they wish to - to reframe post-diagnostic support in a recovery-focused way from the outset, giving a more flexible, peer-led, mental health service.

Section 3. RATIONALE

This research team's members have since 2016, been collaborating closely with users of older adult mental health services, people living with dementia, their family supporters and staff to identify several research priority areas.²⁸ These priority areas emphasised the need for knowledge to reduce potential feelings of abandonment, shame, guilt, despair and hopelessness in people living with

dementia and their families which often follow a dementia diagnosis. Through ongoing dialogues, we have worked with people with lived experience and staff working in memory services and identified that Recovery Colleges could meet these needs, then co-produced the Theory of Change map (Appendix 4) to represent their working hypotheses of *how* Recovery Colleges can function to meet these needs.

As identified, Recovery Colleges are predominately operating within adult mental health services, and currently, next to no literature exists on UK Recovery Colleges adopting a recovery approach for people with dementia. For this application we undertook a brief scoping survey which confirmed mental health Trusts are incorporating dementia into Recovery College programmes²⁹ but lacking evidence on what is required within these programmes to address the problems identified by people living with dementia and their family supporters. For example, what is needed to address social stigma and marginalisation, disempowerment, diminished hope, identity and loss of confidence and feelings of being 'left alone' to adjust to the diagnosis over time. The Theory of Change map underpins this research and includes shifting current ideas about recovery from being incompatible with dementia as a progressive condition, to where 'recovery' in this context refers finding a way to live a meaningful and fulfilling life alongside a dementia diagnosis.³ This we believe, is an innovative and flexible approach for post-diagnostic support, delivered within existing NHS organisational structures by the existing Recovery Colleges. Equally, there are potentially many factors that may impact on engagement and uptake of Recovery College dementia courses, including the terms used to name and describe them. 'Recovery Colleges' are so named to embody a recovery-focused, adult educational approach within mental health services and are the organisational 'vehicle' and international 'brand' name. 10 years on from inception, they are recognised as such within statutory mental health and social care services and partners within the voluntary sector. The term 'recovery' may not immediately sit well within the dementia narrative, and any changes to this term could make the type of activity less well-understood, so identifying the most appropriate terminology is an area we specifically intend to explore. A recovery-focused course within a Recovery College could have a different meaning for people with dementia and their family supporters, so changing titles of actual courses within the Recovery College may be important, as will course duration and delivery methods. As highlighted by a peer reviewer, it would "*...enhance the research to ask not only 'what works for whom under what circumstances,' but also explicitly ask 'what does not work for whom and under what circumstances?'*". We are open to actively seeking out the unexpected findings, and the question of '*do some courses/programmes work well even if not co-produced/co-delivered?*' will also be an important area to consider in the selection of our research sites.

The CHIME Recovery framework, as operationalised through Recovery Colleges, has clearly relevant links with the NICE-recommended person-centred care framework for dementia,^{7,30} the Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP)⁸ and the National Dementia Strategy objective to develop peer support and learning networks.³¹ Key domains for person-centred care are **valuing** people living with dementia and those (both informal family and friends and health and social care staff) who care for them; providing care that is **individualised**; understanding and acting from the **perspectives** of people living with dementia (which can reinforce connections, meanings and identities); and creating positive **social-psychological** environments (which can build hope and empowerment).³² For dementia care to be person-centred, all these elements are needed and need to work together. Both frameworks require mental health services to continuously improve, and to evidence progress towards more meaningful care within each of these domains,^{32,33} yet person-centred principles are still poorly and inconsistently translated into practice. Applying these frameworks in memory post-diagnostic support services is important for keeping a whole person focus, so as to value the identity, perspectives, strengths and needs of people living with dementia, and so to enable staff to more effectively to share with patients care planning alongside understandings of personal recovery in adjusting to dementia.^{20,34}

Section 4. THEORETICAL FRAMEWORK

Realist approaches

We are seeking to understand when Recovery College dementia courses ‘work’, for whom, why and what sort of impacts come from people taking part. To develop such an understanding, we do not need (or indeed want) there to be uniformity in the delivery of dementia courses. Variation in co-production and co-delivery is of great value in helping us to develop our understanding because it will provide data that we can analyse in our evaluation of what is causing different impacts for different people within different Recovery Colleges.

To make sense of this complexity we are using two theory-driven approaches. Firstly, a rapid realist review (Work Package 1) to develop an initial programme theory; and secondly, a realist evaluation (Work Package 2) of five existing Recovery College dementia courses, using multiple data collection methods. Our research methods are context-sensitive, and the programme theory will explain the influences of contextual factors on outcomes. Realist approaches do not assume the intervention alone leads to change, but see change as caused by often-hidden causal ‘forces’ (i.e. mechanisms) that operate differently in specific, conducive contexts. These mechanisms, in turn, lead to outcomes, both intended and unintended. Realist approaches address the complexity of social programmes which rely on people to deliver them and can make sense of wider constraints on activity, including individual, social and organisational factors.⁴⁵ Understanding and identifying differences in the practice and structure of Recovery College dementia courses operating within the constant flux in NHS mental health services are fundamental to explaining the range of outcomes from Recovery College dementia courses for people living with dementia, their family/friend supporters and staff.

Section 5. RESEARCH QUESTION/AIMS/OBJECTIVES WORK PACKAGE 1

Research question:

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

Aims This study has four Work Packages (WP) and this protocol describes WP1. **Primary Outcome:** We aim to develop an in-depth evidence-based understanding, captured in an initial realist programme theory, of how existing mental health service-delivered Recovery College courses and post-diagnostic support structures, lead to intended and unintended outcomes for people living with dementia, their families/ friend supporters and staff. **Secondary Outcome:** Ultimately nearer the end of the study, we will use our programme theory to co-produce appropriate guidance and resources for implementing Recovery College dementia courses, and applying the theoretical models of CHIME and person-centred care in rebalancing shared decision-making within dementia diagnostic processes.

Work Package 1 objectives

- 1** To map the provision of Recovery College dementia courses across the UK.
- 2** To conduct a rapid realist review of evidence from peer-reviewed and grey literature, related theory, policy/practice guidance and key stakeholders, to specify what components characterise a recovery-focused approach to adjusting to a diagnosis and to providing appropriate post-diagnostic support in dementia.
- 3** To identify the key components of effective Recovery College dementia courses in an evidence-based, realist initial programme theory.

Section 6. DESIGN AND METHODS WORK PACKAGE 1

WP1a is a rapid realist review, with mixed methods survey and stakeholder consultation and engagement groups, co-led by Melanie Handley and Geoffrey Wong.

We want to understand how best to implement Recovery College dementia courses to be co-produced and attended by people with dementia, their family/friend supporters and mental health staff. Recovery Colleges currently running in the NHS are a complex intervention with context sensitive outcomes. The mode of delivery, setting, courses, students and use of outcomes differ between colleges. For example, the majority of Recovery Colleges (but not all) have provider partner organisations e.g. colleges, universities and third sector organisations. Courses vary in terms of their venues including on NHS Trust premises, community settings (such as public libraries), local colleges and primary care settings. The courses vary in terms of length from brief one-off 'taster sessions' to longer term courses (e.g. 24 sessions). The majority of Recovery Colleges collect outcome data (e.g. student feedback and standardised outcome measures) but this varies between courses. In WP1a we seek to understand what is currently being delivered in the NHS by using a survey and through the survey invite/recruit post-diagnostic support staff to express interest and form the staff stakeholder advisory group. In WP1b and WP1c we will develop an initial programme theory, that extends the existing Theory of Change map, to identify potential explanatory mechanisms to explain how and why Recovery Colleges are thought to work to help people living with dementia adjust to a dementia diagnosis. This information and initial outcome domains will be taken to, and discussed and deliberated with the two stakeholder advisory groups in WP1c. This iterative, multi-methods, consensus approach provides pragmatic information while exploring controversial and sensitive issues in the absence of empirical evidence. The iterative nature of this approach also offers flexibility and allows new insights to be incorporated into the later stages of the process.⁴⁶

Section 7. SETTINGS, SAMPLE AND RECRUITMENT WORK PACKAGE 1

WP1a. Mixed methods survey • Team: Emma Wolverson, Esme Moniz-Cook, Bonnie Teague, Linda Birt, Chris Fox, Juniper West, Ruth Mills, Kathryn Sams, Research Assistant Psychologist (TBA) Extending our early scoping work,²⁹ we are designing, piloting and surveying all NHS mental health providers of Recovery Colleges and associated memory services across the UK using an online licenced survey platform to gain deeper understanding of current dementia course provision. This will include successes, changes and adjustments, particularly around the COVID-19 pandemic in terms of any online co-production work and course delivery, content, materials, demographics, diversity and engaging with stakeholders to inform case study site selection for WP2. Our initial scoping survey was a service evaluation, which restricted the breadth of information we could collect, but aimed primarily to find out if other Recovery Colleges around the UK were offering dementia courses, check out the feasibility of approaching other sites to potentially recruit and inform our study design, and to invite expressions of interest in our proposed research. Recruitment to a simple email with a survey link yielded a good return of 32.5%. Although we have maintained contact with the 7 Recovery Colleges that expressed interest in remaining involved from our scoping survey, what they are currently offering in the way of dementia courses may have changed. Several however offered recent updates on the impact of the COVID-19 pandemic on the delivery of dementia courses. WP1a with full REC approval will expand the range and depth of our survey questions.

We will run two surveys: 1) Recovery Colleges and 2) NHS memory services. We will define what we mean by reasonable percentage survey response rates and set these as targets. We will take care to design the surveys to be clear, succinct and accessible, and to pilot these with input from PPI advisors, Recovery College and clinical team colleagues from memory services in the sponsor organisation NSFT,

and respond to user feedback. Emma Wolverson is employed by Humber Teaching NHS Foundation Trust which has an active Recovery College in the North of England, and Ruth Mills and Kathryn Sams have leadership roles within NSFT's clinical memory services and directly support and encourage staff to be involved with the Recovery College. Their combined experiences and regular reviews together with the SSC can offer expert advice on engaging with the Recovery College community to boost responses. For the NIHR200605 study (which began in December 2020) the RECOLLECT2 team ran a national survey of all Recovery Colleges in England, as well as a separate international survey of all Recovery Colleges in all other countries. RECOLLECT2 Co-Lead Professor Mike Slade has kindly linked us with other members of the RECOLLECT2 study team to collaborate with us in terms of sharing best ways of identifying all Recovery Colleges (i.e. the denominator for our survey). As part of survey work we will need to understand which memory services map against which Recovery Colleges by including geographical survey questions e.g. 'which memory services do your NHS Trust Recovery College cover? We can then map and survey the memory services against data from Recovery Colleges to join up information on how they work with the Recovery College in their area, potentially using Likert scales - i.e. rate the strength of your relationship with your memory service <> Recovery College. To give an idea of the types of questions we will be asking, early draft indicative questions can be found in Appendix 3.

We will use internet-based and social media approaches to survey publicity, recruitment and engagement. Additional ideas for boosting survey completion include a recruitment communication strategy to introduce the survey and the study involving materials co-produced with our PPI advisory group to be available by audio and video, using our in-house producer within NSFT R&D, as well as wider advertising through the Memory Services National Accreditation Programme (MSNAP) and the Recovery College community via Implementing Recovery through organisational Change (IMRoC) networks as suggested by one of our interested Recovery Colleges. We will regularly review progress towards meeting our percentage target and if after 1 month, if and where we are falling short of that target, we would take a proactive approach by following up and contacting individual Recovery Colleges and memory services with follow up emails and telephone calls, supported by the DiSCOVERY research assistant psychologist. The issue of data burden for survey respondents is particularly important within the context of the backlog of NHS routine care caused by existing mental health service delivery pressures exacerbated by the COVID-19 pandemic, the pressure on Recovery Colleges through adapting to new ways of working (i.e. moving on and off online) and on-going uncertainties around future direction and impacts. We will seek to identify key contact people and offer to support and facilitate individual survey data collection via telephone if needed. One risk could be in not enough diversity of responses, which would limit purposive sampling, and would need to be considered in the research outputs. We could also work with stakeholders who deliver the Recovery Colleges as well as those who deliver and use dementia services to develop the programme theory to bolster any shortfalls in actual Recovery College courses for dementia, as the development of programme theory is inherently theoretical and can include diverse forms of data.

Steps to mitigate against a poor survey response We will take care to design and pilot the online survey with the responders in mind, e.g. by clearly stating points about purpose, aims, consent, data protection, how long the survey will take to complete and how and where to obtain the results. We will carefully plan a communication and recruitment strategy alongside, which will target specific communities with high prevalence of dementia. A low uptake on the survey will not have statistical consequences relating to the progress of the study, but will only impact generalisability of our understanding of Recovery College dementia course provision.

Quantitative data will be analysed in SPSS version 24. Descriptive statistics will be calculated (means and standard deviations or medians and interquartile ranges) using tables and graphs to display data. Qualitative data will be analysed in Microsoft Excel using basic content analysis⁴⁷ to descriptively

summarise the broad types of responses given. Phrases within open-ended responses for each question will be inductively coded by one researcher grouped under the same topic, discussed with the wider team members to agree coding and quantified using frequency of responses within that code. Recovery Colleges will be asked to provide demographic information/estimates about the users of their dementia courses relating to age, gender, ethnicity and cultural background and socioeconomic indicators. This will be compared with regional demographic characteristics and socioeconomic factors to assess equitable representation and inform study analysis. Exploration of key outcome measures used in services and staff views about these will be included in the survey. The survey will ask key demographic information from clinical staff participants (e.g. age, gender, professional background, years since qualification) and will target recruitment strategies for staff groups who are underrepresented in responses, assessed at regular intervals. The survey will also function as a recruitment tool for inviting expressions of interest to join the staff stakeholder advisory group.

WP1b. Rapid realist review • Team: Melanie Handley, Geoffrey Wong, Claire Duddy, Corinna Hackmann, Esme Moniz-Cook, Research Assistant Psychologist (TBA) We will synthesise evidence from diverse sources (i.e. academic/grey literature, policy, related theory) to build an initial programme theory of a recovery-focused approach to adjusting to a dementia diagnosis and associated post-diagnostic support. The initial programme theory will be developed with input from the two advisory groups (see WP1c below). Our five-step rapid realist review is adapted from Pawson's suggested steps^{48,49}, achievable in our given timeframe because our focus is very narrow; to develop an initial rather than a highly detailed 'finalised' programme theory. The rapid realist review protocol is registered with PROSPERO (CRD42021293687), and can be accessed here: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=293687

Step 1: Translate the existing Theory of Change map for Recovery College dementia courses into a realist initial programme theory. We will do this through one to two half-day meetings with all members of the project team, using the project team's content expertise to generate potential realist causal explanations which fit with the existing theory of change and specify elements of a person-centred approach in dementia³² and the CHIME framework.²¹ We will focus on explanations relating to Recovery College dementia course planning, delivery and outcomes.

Step 2: There will be a rigorous search strategy which will encompass both published and grey literature. There will be no restrictions on the types of study (study design) eligible for inclusion. We will undertake highly focused searches of electronic databases (e.g. PubMed, CINAHL, PsycINFO), and keyword searches on Google Scholar, NIHR and other relevant websites (e.g. DEEP) to identify documents that contain data that we can use to refine the initial programme theory developed in Step 1. We will identify relevant policy/practice guidance from online searches of NHS and mental health service websites and through the knowledge of key informants and the research team. Searches for peer reviewed literature regarding self-management and peer support in dementia will be complemented by including areas of self-management and peer support from other conditions, for example adult and older people's mental health, and we intend to scope reports and articles from organisations across the health system, including voluntary and community sector organisations. Claire Duddy - experienced librarian and realist reviewer - will work with the project team to develop, pilot and refine search strategies based on Step 1 outputs. We also recognise that a lot of literature in this area will not be published in peer reviewed journals, so we will include internet searches to capture blogs and vlogs produced by people living with dementia. For example, by Peter Berry, who is involved in co-producing a Recovery College dementia course in NSFT's East Suffolk Care Group, and is a member of our PPI advisory group <https://dementiadiaries.org/diarist/peter-berry> and Wendy Mitchell from the Humber Recovery College Raising awareness | Which me am I today? (wordpress.com). We will download documents to reference management software (e.g. Endnote). One researcher will

screen using the inclusion and exclusion criteria in two-stages: first screening by title and abstract and then by full text. **Inclusion:** People with dementia and their supporters who co-produce and/or attend Recovery College courses, mental health staff who co-produce and/or attend Recovery College courses **Exclusion:** Participants without a diagnosis of, or supporting those with, dementia, therapy groups. To ensure the screening process is a consistent, another research team member will check a 10% random subsample for systematic errors. We will include documents which i) relate to Recovery Colleges/ recovery approaches; ii) are delivered in the NHS and; iii) contain relevant empirical data and/or theory. We will only run additional searches if required, to identify data to address specific gaps or refine specific aspects of the initial programme theory.

Step 3: A single member of the research team will select and appraise documents, applying the following criteria to documents included at the full text stage:

- Relevance: Are sections of text within this document relevant to programme theory development?
- Rigour: Are these data sufficiently trustworthy to contribute to programme theory development?

Step 4: A single researcher will extract data from relevant documents as follows: i) descriptive data describing the included documents (e.g. date, type of document, study design, etc.) which will be tabulated in Excel and; ii) extracts of relevant data from full text documents which will be uploaded into software that assists qualitative data analysis (e.g. NVivo). Another research team member will check a 10% random sample for systematic errors.

Step 5: A single researcher will lead data analysis and synthesis with regular discussions with the research team to challenge and debate interpretations. A realist logic of analysis, used to develop potential context-mechanism-outcome configurations, will explain when, why and how Recovery Colleges might lead to intended (and unintended) outcomes. To operationalise this logic we will ask these questions:

- Interpretation of meaning: do the contents provide data that may be interpreted as functioning as context, mechanism or outcome?
- Interpretations and judgements about context-mechanism-outcome configurations (CMOCs) e.g. what is the CMOC for the data that has been interpreted as functioning as context, mechanism or outcome?
- Interpretations and judgements about programme theory e.g. how does this CMOC relate to the theory of change and/or the initial programme theory?

We will seek data to inform the interpretation of the relationships between contexts, mechanisms and outcomes across documents. Interpretive cross-case comparison will be used to understand, and explain how and why observed outcomes have occurred, for example, by comparing the success of implementation of Recovery College courses in different settings or groups. Juxtaposing, reconciling, adjudicating and consolidating data will be used.

WP1c. Stakeholder Advisory Groups consultation and deliberation • Team: Melanie Handley, Linda Birt, Rachael Litherland, Juniper West, Ruth Mills, Kathryn Sams, Research Assistant Psychologist (TBA) Information sheets will be sent to potential stakeholder advisors that set out details of why they have been invited to the advisory group and what their involvement in the group will entail, and valid informed consent obtained. We will draw on members' lived and learned experience, knowledge and expertise by asking for feedback and advice on our findings, to inform data collection in WP2 and throughout the whole study. In two two-hour online meetings facilitated by Melanie Handley, Linda Birt, Rachael Litherland, Juniper West, Ruth Mills and Kathryn Sams we will share and discuss the developing CMOCs with the PPI and staff stakeholder advisory groups. PPI meetings may be shorter in duration if required. The two consultation and deliberation events presenting the same findings, will be open to all members from both advisory groups and will be

conducted on different days and times (e.g. morning/afternoon) in the same week to maximise attendance. Online platforms (Zoom/Microsoft Teams) will be used to conduct discussions of how stakeholder advisory group members experiences of preparing, implementing and/or attending dementia courses in Recovery Colleges across the UK compare with the developing findings of the review.

Discussions will take place in online breakout rooms of up to six people, organised by attendee knowledge and expertise (e.g. PPI member, staff role) to gather the variety of perspectives and experiences. One facilitator will be allocated to each online breakout room to present findings using materials, such as vignettes, that set out the CMOCs in an accessible format. Facilitators will support engagement with discussions, make notes and feedback to all attendees at the end of the breakout groups. With permission from breakout groups, discussions will also be audio recorded to support analysis. In addition, notes from discussions, comments posted on the event chatroom or comments offered after the event will be collated and discussed between the event facilitators and the rapid realist review team (WP1b) to identify if there are key areas of divergence and/or agreement with the developing programme theory. This deliberation process will allow us to assess how far and where findings may resonate with group members' diverse experiences and assumptions.

Outputs from Work Package 1: initial programme theory informing data collection and analysis in WP2 & 3 • findings from UK-wide survey on Recovery Colleges informing purposeful sampling of Recovery College case study sites in WP2 • summary of outcome measures reviewed against programme theory to inform WP3

Section 8. ETHICAL AND REGULATORY COMPLIANCE

Obtaining valid informed consent Based on the extensive experience of the research team, specific ethical issues will relate to obtaining valid informed consent from people with dementia, their family/friend supporters and mental health staff to cover General Data Protection Regulations⁵⁰ for collecting data including recording audio-visual work, from discussions and deliberations taking place in online meetings and smaller group 'breakout rooms' which will support research data analysis throughout the various stakeholder engagement activities. As well as holding a PPI role throughout the study the PPI advisory group will also take part in similar research activities, therefore, valid informed consent will be obtained, or a consultee declaration form completed in the event that a person lacks, or experiences fluctuating capacity.

The WP1a. surveys will include a short introductory paragraph containing sufficient information to enable potential participants to reach an informed decision whether to complete the survey or not. The information will describe the nature and purpose of the research, why they are being invited to take part, how the information collected will be used and stored, and how the findings will be made available to them. Completion of the survey will indicate consent on behalf of the participant.

Supporting stakeholder advisory group participants We have procedures for researchers on how to recognise and manage potential distress while working with individuals and groups remotely, for which specific practice guidance has been published by members of the team.⁵¹

Obtaining necessary approvals NHS Health Research Authority approval will be obtained before commencing research.

Person-centred approach In engaging with people living with dementia, we acknowledge that people living with dementia and their family/friend supporters have been more isolated than usual during the COVID-19 pandemic. There may be reluctance to participate in WP1 study activities including joining

the PPI advisory group and associated stakeholder engagement activities in WP1c. or attending Recovery College dementia courses. Our team has considerable experience of solving issues with recruitment of people with dementia and family/supporters to research studies, for example <http://www.perfected.ac.uk>. We understand that deciding whether to take part in research or not can be complex if a person is experiencing cognitive impairment. We have mitigated this by taking a person-centred approach to information sharing, consent processes and interviewing. For example, by building rapport, taking time, being mindful, adopting process consent methods,⁵² valuing people's contributions and ensuring a positive research experience.

We equally acknowledge the extra pressures the COVID-19 pandemic is placing on mental health staff and service and potential impact on recruitment to the staff stakeholder advisory group via the WP1a. surveys. Chris Fox, Juniper West, Corinna Hackmann, Ruth Mills and Kathryn Sams work within clinical mental health services and we will seek on-going advice and monitoring through regular team and expert Study Steering Committee meetings. We are aiming to form a staff stakeholder group for the duration of the project so people can feel fully involved and invested in the project. To acknowledge and value people's contributions we have a) included in the costings reimbursement for their time which can be paid to them personally in the form of vouchers; b) propose to offer certificates for the purposes of revalidation, appraisal, promotion, evidence of research involvement for their professional development plans; and c) offer co-authorship on papers where applicable within authorship guidelines, and to be named on output reports. We will ensure our communications are clear, and information and recruitment materials are accessible, and adapt our wording and language as deemed necessary by our PPI advisors.

Language and wording In terms of bringing together people with dementia, their family/friend supporters and staff participants from multiple services who may or may not be connected (Recovery Colleges and post-diagnostic support/memory services), we assume some acceptance of the terms 'Recovery' and/or 'Recovery Colleges' in relation to dementia. We will ensure our communications, information and recruitment materials are accessible and adapt our wording and language as deemed necessary by our PPI advisors. One development from previous work which proved successful was developing a glossary and definition of key terms which have been co-produced with mental health service users and families/supporters, clinicians and academics.

Equality, diversity and inclusion As part of the NSFT's R&D departmental inclusion and equality strategy across the lifespan, focus groups and interviews with under-served and ethnic minority family supporters of people with dementia were held during January 2021. Family members expressed it as important to include the voices of under-served groups so as to ensure that health research and service improvements reflect groups' unique needs and outcomes. The group highlighted the importance of incorporating cultural and life histories into the design of clinical interventions from the start of the research process. This was felt to be particularly important for older people who have traditionally been marginalised in the development and conduct of health research, and subsequently experience health care models and services that do not account for their needs. It was suggested to include 1:1 introductory meetings between researchers and PPI advisory group members, including trusted family members, to discuss life histories, build a trusting relationship and ensure that involvement representatives feel comfortable. Suggestions for engaging stakeholders included integrating study promotion with elements of health literacy education around dementia within the awareness campaigns, as many diverse groups want more knowledge of the symptoms and support available for dementia and will therefore be more likely to engage in initiatives which appear to have a direct benefit. Other suggestions included:

- 1) Paying for extra support/time in order to participate in research activities;
- 2) Using trusted translators (family or professional) to support inclusion of stakeholders who may have communication or language needs;

3) Providing a technical help session and training for any online work to support older people to take part in the study activities is essential.

Section 9. DISSEMINATION POLICY

What we intend to produce from our research; how we will inform and engage stakeholders and the wider population about our work; how we will share with study participants the progress and findings of our research and how our outputs will enter the mental health care system and society as a whole

Materials, for example, study web pages and flyers calling attention of potential participants to the research will be co-designed for the format to be dementia-friendly, with members of the PPI advisory group, using wording from the Plain English summary of research on page 9.

Stakeholder engagement will be via the two stakeholder advisory groups established at project start as described, and will be embedded throughout the whole project, including sharing progress with study participants through to disseminating findings. Where we want to include a wider range of dissemination activities from people with dementia, we are connected to people via Racheal Litherland and Innovations in Dementia, who host DEEP. Rachael Litherland and the PPI stakeholder advisory group will be central to the communication and interaction with the DEEP network.

The project is affiliated to the NIHR ARC Eastern Inclusive Involvement in Research theme which also supported time for Fiona Poland and Linda Birt to work on the funding application.

WP1 will produce an initial programme theory to identify potential mechanisms to explain how and why Recovery Colleges are thought to work when adjusting to a dementia diagnosis. This work will be appropriate for publication in relevant peer-reviewed high impact journals (e.g. Aging and Mental Health, Gerontologist, Dementia) and dementia care practice journals (e.g. Journal of Dementia Care, Faculty of Psychology for Older People).

We will draw on a basic framework available from Parkinson's Disease UK who developed a toolkit, through extensive work and user testing, to help keep research participants updated. Basic principles include: hearing from the research team every three months about the research study itself, research time points, future plans and links to information about symptoms and useful support relevant to the research, all preferably via email or on a website [Staying connected - toolkit.pdf \(parkinsons.org.uk\)](#)

Linking our theory with the Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP) <https://www.rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/memory-services-national-accreditation-programme-msnap#:~:text=MSNAP%20is%20a%20quality%20improvement,Become%20part%20of%20the%20Network>

MSNAP is a quality improvement and accreditation network for services that assess, diagnose and treat dementia in the UK. It provides an evidence and practice-based set of standards against which individual services can self-review progress towards meeting in preparation for applying for formal accreditation. The standards are currently on the 7th Edition and due for revision in 2022. They are reviewed regularly in light of policy and any issues identified from the practice of accreditation and from the multi-disciplinary standards development group which includes patients and the public, MSNAP members from services and partner organisations. We have established close links with Professor Martin Orrell, Director of the Institute of Mental Health, University of Nottingham and Chair of the Memory Services National Accreditation Panel. The Royal College of Psychiatrists holds an annual National Memory Services Forum, which brings together professionals working within memory services for an opportunity to review MSNAP developments made in the past year and discuss popular

topics in relation to dementia assessment, diagnosis and follow-up care. Professor Orrell has invited our project team to present our initial programme theory of a recovery-focused approach to post-diagnostic support in dementia at the next appropriate online webinar. This will provide an excellent forum to engage with a key clinical audience at an early stage of our research. The talk would be co-presented by members of the WP1 team and PPI advisory group members supported by Rachael Litherland if they are comfortable with this and/or through making and using short embedded film clips.

Linking with the Dementia Change Action Network (DCAN) <https://dcan.org.uk/> DCAN is a joint initiative by NHS England & Improvement, the Alzheimer's Society and the Coalition for Collaborative Care. They are an open network consisting of people with professional or lived experience of dementia, aiming to change how we all talk, think and respond to dementia. They are opportunities to share study findings at DCAN events, as well as on their website.

Linking with Q Community of Practice <https://q.health.org.uk/> Q is an initiative led by the Health Foundation to support the promotion of improvement with the health and care system. Q supports initiatives and programmes by making it easier to understand what improvement work is being done, by whom, and where; providing resources and platforms to connect and support across existing networks; making it easier to collaborate on areas of shared interest; and influencing the context of improvement. Study findings could be presented to members at Q events and published on their website.

Links with INTERDEM <http://interdem.org/> INTERDEM is a pan-European research network on early, timely and quality psychosocial Interventions in dementia. Esme Moniz-Cook is INTERDEM founder and Board co-chair; Chris Fox is an INTERDEM Board members and Emma Wolverson is a member of INTERDEM. Study findings will be presented at INTERDEM meetings.

Study milestone findings will be shared with mental health post-diagnostic support services, Recovery Colleges, FPOP and MSNAP through talks with Innovations in Dementia, DEEP, and with other local and other organisations following guidance from our PPI advisory group, and wherever possible including an interested member of this group in presentations. This will include making and using short embedded audio recordings and/or film clips to support accessibility for people living with dementia and their family/friend supporters as suggested through our consultations with people with dementia and their families and members of our expert Study Steering Committee. We will collaborate with DEEP to ensure all materials are accessible for people living with dementia and Open Access, publicly accessible via NSFT, partner universities and NIHR ARC through the use of newsletters, leaflets, webpages, network sites such as DCAN, social media and where relevant different languages and formats (for example vlogs and blogs).

Having previous experience of participating in Department of Health & Social Care consultations we will contact key policy groups to support important messages regarding our work. The research team have extensive links at national and regional levels and are already engaged with healthcare planners and practitioners who will be informed regarding progress. UEA Health Partners is a collaboration between academics, clinicians, commissioners, local authorities and service providers across both health and social care. This group will be important in translating and promoting this research into practice across East Anglia with reach across the UK. We will continue our close and ongoing collaboration between our team and the NIHR Eastern Applied Research Collaboration Implementation team, including through the development of this proposal, to support rapid learning.

Intellectual Property There is no identified background IP. NSFT has assigned a Business Manager to oversee and manage the foreground IP aspects of this project. They will work with the team

during the lifetime of the project to ensure that any new IP/know-how developed is well-positioned to maximise patient benefit. Foreground IP based on results of this study will be owned by the lead organisation NSFT, however the website hosted by NSFT will contain Open Source online resources which will retain a copyright strapline, and be available as a pack for Recovery Colleges via ImROC. A collaborative agreement, to be signed by all partner organisations, will detail the conditions under which partners may use the outputs and know-how of the study for research and non-commercial purposes.

Archiving The investigators agree to archive and/or arrange for secure storage of study materials and records for 10 years after the close of the study unless otherwise advised by the Sponsor NSFT.

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Section 11. APPENDICES

Appendix 1 • Study Steering Committee (SSC) Terms of Reference

The following definitions and roles have been adopted from the National Institute for Health Research (NIHR) Research Governance Guidelines (Version 2 September 2021) and will be used for Norfolk and Suffolk NHS Foundation Trust (NSFT) sponsored qualitative studies which have been funded by the NIHR.

The role of the Study Steering Committee is:

To provide overall supervision for a project on behalf of the Project's Sponsor (NSFT) and Funder (NIHR) and to ensure that it is conducted to the rigorous standards set out in the Department of Health and Social Care's Research Governance Framework for Health and Social Care and the Guidelines for Good Clinical Practice.

The day-to-day management of the project is the responsibility of the Chief Investigator/s, and as such the Chief Investigator/s have set up a separate Project Management Group (PMG) to assist with this function.

The main features of the Study Steering Committee are:

- To provide advice, through its Chair, to the project's funder, sponsor representative, Chief Investigator/s, host institution, and contractor
- To concentrate on the project's progress, adherence to the protocol, and participant safety (where appropriate), and to consider new information of relevance to the research question
- The rights, safety and well-being of the participants are the most important considerations and should prevail over the interests of science and society
- To ensure appropriate ethical and other approvals are obtained in line with the project plan
- To agree proposals for substantial protocol amendments and provide advice to the sponsor and funder regarding approvals of such amendments
- To provide advice to the investigators and the study Project Management Group (PMG) on all aspects of the project

Constitution:

- The relevant NIHR Programme Director will review the nominees and appoint the Chair and members
- Independent members must make up a minimum of 75% of the Committee membership
- The minimum quoracy for any SSC meeting to conduct business is 67% (two thirds) of the appointed membership
- Only appointed members will be entitled to vote (irrespective of their level of independence) and the Chair will have a casting vote
- The Chair and members must sign and maintain a log of potential conflicts and/or interests
- Attendance at SSC meetings by non-members is at the discretion of the Chair
- The primary SSC reporting line is via the Chair to the relevant NIHR Programme Director; however, communication is likely to be between the Chair and the NIHR Research Manager who has day to day responsibility for the project.

Note: We advise keeping the number of members on your SSC to an easily manageable number, but preferably to no more than 8 members in total.

Composition:

- An Independent Chair (UK based and/or holding a substantive UK based appointment)
- At least one (preferably two) Public or Patient member(s), preferably independent.
- Others with clinical or other expertise relevant to the project, such as health economics, social care, public health etc.
- Ideally, the SSC should invite observers, including representatives of the sponsor and research network to meetings

Meetings:

- Although there may be periods when more frequent meetings are necessary, the SSC should meet at least annually in person and/or online
- Meeting minutes should be sent to all members, the sponsor, and the funder, and be retained in the study master file
- The responsibility for calling and organising SSC meetings lies with the Chief Investigator/s, in association with the Chair. The NIHR reserves the right to attend any meeting, therefore should be included in relevant invitations. In exceptional circumstances there may be occasions when the Project Sponsor or NIHR will organise and administer these meetings.

The role of the Chair

The Chair of the SSC is directly answerable to the relevant NIHR programme, as funder. The Chair's responsibilities include:

- Liaising with the Chief Investigator/s to arrange a meeting to finalise the protocol and to set up a schedule of meetings to align with the project plan
- Establishing clear reporting lines to the Funder, Sponsor, etc.
- Being familiar with relevant guidance documents
- Providing an independent, experienced opinion if conflicts arise between the needs of the research team, the funder, the sponsor, the participating organisations and/or any other agencies
- Leading the SSC to provide regular, impartial oversight of the study, especially to identify and pre-empt problems
- Ensuring that changes to the protocol are debated and endorsed by the SSC; letters of endorsement should be made available to the project team when requesting approval from the funder and sponsor for matters such as changes to protocol
- Being available to provide independent advice as required, not just when SSC meetings are scheduled
- Commenting on any extension requests and, where appropriate, providing a letter to the funder commenting on whether the extension request is supported or otherwise by the independent members of the Committee
- Commenting in detail (when appropriate) regarding the continuation, extension or termination of the project.

Note: *The SSC Chair does not need to be a content expert but needs to ensure that sufficient content expertise is available for the group to perform its oversight function effectively.*

Definition of a public member

The public members of SSCs are ideally people who have lived experience of the subject being researched, or who have other relevant experience that will add value to the conduct of the study. This may include people who have experience of a particular condition or service as a patient or a carer, or members of the public who are affected by the issues being researched. Public members should not be patients of a clinician on the research team or SSC.

Independence

Independence is defined as follows:

- Not part of the same institution as any of the applicants or members of the project team
- Not part of the same institution that is acting as a recruitment or investigative centre, including Patient Identification Centres (PIC), identifying and referring patients to a recruitment or investigative centre
- (In both cases above 'not part of the same institution' means holding neither a substantive nor honorary contract or title with said institution)
- Not related to any of the applicants or project team members
- No other perceived conflicts of interest
- For the Chair only; not an applicant on a rival proposal
- It is recognised that independence status of individual members of the above committees may change during the duration of the project, and it is the responsibility of the Chief Investigator/s to ensure that the funder is notified of such changes.

Other Oversight Groups

Project Management Group (PMG)

The PMG is responsible for the set-up, routine running and analysis of the research and is usually made up of the research team. The PMG meet regularly, typically monthly, and review the ongoing progress and conduct of the study including:

- Progress of study and site opening
- Recruitment rate (actual versus predicted)
- Site issues
- Data quality and return rate
- Protocol amendments
- General research study issues

Public role: The PMG may have a public member who is a member of the research team and has research management responsibilities. They may also have been a public co-applicant on the research funding application. There may be other members of the public involved in the undertaking of the research in advisory or research activity roles.

ENDS

Appendix 2 • Representative Inclusion, Participation and User Involvement Study Strategy (REP-US)

Study: Post-Diagnostic Dementia Support within the ReCOVERY College Model: A Realist Evaluation (DiSCOVERY)

Background to inequalities within target study population

- By 2026, there will be an estimated 50,000 people from ethnic minority groups living with dementia in the UK, a figure rising much more rapidly than in the general population (House of Commons, 2013). Ethnic minority groups are under-represented in dementia services, and are often diagnosed at a later stage in their illness.
- A recent study (Dodd et al, 2020) found that compared to white British groups, ethnic minority groups were less likely to receive a cognitive assessment and if they did, received lower scores. Ethnic minority groups were less likely to be offered or use post-diagnostic community support for dementia than white British ethnicity.
- Nielsen et al, 2020, reported that Danish dementia care coordinators felt that offering post-diagnostic services to ethnic minority people with dementia was 'challenging' and provision to mitigate language or cultural barriers was lacking. This meant that most post-diagnostic support would fall to families of ethnic minority people with dementia.
- No research has been found examining the impact of socioeconomic factors or deprivation on post-diagnostic dementia support.

Work Package	Summary of REP-US activity
WP1a	Recovery Colleges will be asked to provide demographic information/estimates about the users of their dementia courses. This will be compared with regional demographic characteristics and socioeconomic factors to assess representation and inform study analysis.
	Health professionals in memory services survey will ask key demographic information from clinical staff participants and will target recruitment strategies for staff groups who are underrepresented in responses, assessed at regular intervals.
WP1c	Stakeholders will be purposively sampled by gender, age, ethnicity and socioeconomic status to reflect UK-wide demographic characteristics, taken from PH Fingertips and recruited using targeted information and engagement campaigns for specific characteristics.
WP2	Site selection: 5 x Recovery College sites will be selected to diversely represent the UK population based on information collected in WP1a, as assessed by ethnic minority % of area, socioeconomic and deprivation indices, urban/rural population.
	Participants will be selected from available pool of college tutors and attendees to be representative of gender, age, ethnicity and available socioeconomic indices where possible.
WP3	Outcome measure stakeholders will be purposively sampled by gender, age, ethnicity and socioeconomic status to reflect UK demographic characteristics, taken from PH Fingertips and recruited using targeted information and engagement campaigns for specific characteristics. Outcome measure assessment will include how culturally sensitive and transferable measures are for different cultural groups.

WP4	Programme Theory validation and co-production stakeholders will be purposively sampled by gender, age, ethnicity and socioeconomic status to reflect UK demographic characteristics, taken from PH Fingertips and recruited using targeted information and engagement campaigns for specific characteristics. Co-production of materials will be conducted with specific key demographic groups separately or integrated to reflect the needs of different cultural and ethnicity groups as identified by stakeholders across all WPs.
Dissemination	Specific dissemination and engagement materials and campaigns will be produced for specific ethnic minority and cultural groups as appropriate. All publications and outcome will specifically report on the views and experiences of different groups.

User Involvement Representation Strategy

Representative user involvement work undertaken so far:

In January 2021, we undertook focus groups and interviews of under-served and ethnic minority carers of people with dementia in preparation for the study. The carers expressed that it was important to include the voice of under-served 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. This was felt to be particularly important for older people who have traditionally been marginalised in the development and conduct of health research, and subsequently experience health care models and services that do not account for their needs. The groups raised that the impact of living with dementia is not openly discussed in certain under-served 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.

Additional suggestions which have been incorporated into the design of the study include:

- Paying for respite care/time in order to participate in research.
- Suggestions for engagement of stakeholders include integrating study promotion with elements of health literacy education around dementia within the awareness campaigns, as many diaspora groups, particularly from South Asia, would like more knowledge of the symptoms and support available for dementia, and will be more likely to engage in initiatives which appear to have a direct benefit.
- It is important to consider the needs and involvement of the wider family within user involvement panels for underserved groups, rather than viewing person with dementia-carer relationships as a dyad only. Younger family members play an important role in influencing older members to take part in research and changing community attitudes and it is important that they are included in both participation and user involvement.
- Use of trusted translators (Family or professional) to support inclusion of Stakeholders who may have communication or language needs. To facilitate this, we have included a small budget to support translation and interpretation services on the study. It was recommended that having explanatory audio and video materials are also preferable to support written documentation.
- For any online work, a technical help session and training to support older people to take part in the study activities is essential.

Representative user involvement plans during design and conduct of the study:

- National study user involvement groups will aim to be demographically and culturally representative of the target population. This will be monitored by comparing user involvement characteristics with publicly available demographic data for each participating region, to ensure that there is a representative mix of gender, age groups, ethnicity and socioeconomic status.

Areas which are identified to be under-represented during recruitment will be pro-actively engaged to support involvement (See recruitment strategies below).

- We will include 1-2-1 introductory meetings between researchers and user representatives, including trusted family members, to discuss life histories, build a relationship and ensure that the involvement representatives feel comfortable and ensure their needs are being met.
- If requested in areas with specific ethnic minority, language or cultural identities, we will set up separate male and female user involvement panels, as older females from underserved groups are unlikely to speak openly about their feelings and experiences in front of unknown men and will be less likely to participate.
- Additional meetings with user involvement panels will explore culturally specific language aspects of the research study, including how to describe dementia itself, wider language used in study materials, myth-busting and overcoming stigma.
- Focus group carer participants spoke about their struggle to find time to be part of research groups without dedicated respite support to help ring-fence time for reading/viewing study materials and participating in meetings. To support this, we will include a reimbursement allowance to help respite care to be arranged and paid for, without any financial penalty to the user participants. Any meetings will be arranged to be mutually convenient to the user involvement panel, regardless of day or time. It was mentioned, for example, that evenings may be better.

Recruitment of Sites, Participants/Stakeholders and User Involvement panels

Site Selection and Participation:

Five Recovery College sites will be purposively selected to participate in the case study. The 5 sites will be selected from the wider pool of Recovery Colleges (n=85) to ensure diverse representation of ethnic minority population, urban-rural environments and socioeconomic/deprivation factors. One limitation of the study is that we will only be able to recruit participants from the cohort of Recovery College dementia course co-producers and students who are attending each site, so opportunities to purposively sample participants will be limited. However, selecting sites with diverse population demographics will reduce the risk of participants not reflecting the target population. We will ask all participating sites to collect and share routine demographic data about their students so we can evaluate representation within the study.

User Involvement and Stakeholder Participation:

DiSCOVERY user involvement panel members and stakeholders will be purposively recruited by gender, age, ethnicity and socioeconomic status to produce a cohort which is representative of the target population. To achieve this, raising awareness of the research study in specific communities is critical. There will be complementary recruitment campaigns using visual and audio media for both research participants and user involvement panels across community partnerships, local radio and newsletter promotion, faith leaders in the participating regions and social media campaigns to raise awareness in younger family members. We have previously used this model successfully to support vaccine uptake in the host region by filming short videos and podcasts with local community faith leaders. Suggestions for engagement from user involvement work include integrating study promotion with elements of health literacy education around dementia within the awareness campaigns, as many diaspora groups, particularly from South Asia, would like more knowledge of the symptoms and support available for dementia, and will be more likely to engage in initiatives which appear to have a direct benefit. We will engage trained community health volunteers to support this work in parallel with the core study promotion activities at no cost to the study. Practical barriers identified by focus groups include not having the time to participate in user involvement panels, language barriers and use of technology. Suggested ways to overcome these barriers include:

- Paying for respite care/time in order to participate in research.
- Use of trusted translators (Family or professional) to support inclusion of people who may have communication, language and/or cognition needs. To facilitate this, we have included a small budget to support translation and interpretation services on the study. It was recommended that having explanatory audio and video materials are also preferable to support written documentation.
- For any online work, a technical help session and training to support older people to take part in the study activities is essential.
- We will also ask participants and their families about their life histories in order to provide person-centred care through the research, and anticipate supporting changing language and cultural needs as dementia progresses, as many older people with dementia were born outside of the UK. We routinely use a Cultural Needs Assessment for all research participants so that we can work with people in a person-centred, culturally-sensitive and respectful manner, and this will be adapted for use for this study.
- A shared language glossary will be created to be used and refined throughout the study.

Analysis and dissemination of study findings

- We commit to analysing and reporting results broken down by ethnicity, gender, socioeconomic status and age and will explore limitations in data collection as well as differences in outcomes and views by these groups.
- Recognising that feedback to communities is key to engagement and relationships, specific progress and outcome reports will be written and provided in media and languages preferred by participants, which will be asked for at the time of involvement. Findings will be presented by members of the research team to community partners within each site.
- We have previously undertaken co-production work to create and disseminate research booklets, by integrating drawn art and thoughts about research into booklets which are then distributed to target populations. This has proven to be effective to engage young people and parents, and we would adapt this approach to work with older communities for this study as part of a wider community engagement project to develop podcasts, short videos and visual materials relating to study outcomes.

Monitoring and Evaluating User Involvement and Representation

- As part of routine auditing processes during and after the conduct of the study, we will include user involvement and stakeholder evaluation forms to assess demographic and cultural characteristics of representatives and stakeholders, and compare experiences/outcomes of involvement through standard NSFT RIEVA (Research Impact Evaluation) protocols. This audit will be fed back to the steering group and will be used to improve the involvement and experiences of both user involvement representatives and participants.

Management and Oversight

- The implementation and accountability of the REP-US plan for DiSCOVERY will be overseen by Bonnie Teague with Juniper West and reported to the Study Steering Committee, and NSFT's research committee. Progress on EDI objectives will also be reported to the RISE Programme, the research arm of the Norfolk and Waveney Mental Health Inequalities board, of which Bonnie Teague is a member.
- The study will be subject to a research audit by the sponsor (NSFT), one of the criteria being the representative characteristics of participants and stakeholders.
- The study representation will be included in a publicly available annual report on the lead organisation website regarding research participation and EDI.

References

House of Commons (2013) Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities. Available from: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/appg_2013_bame_report.pdf

Dodd E, Pracownik R, Popel S, Collings S, Emmens T, Cheston R. (2020) 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 Soc Care Community*. (E-print, 21 Sep 20)

Nielsen TR, Nielsen DS, Waldemar G. (2020) Barriers to post-diagnostic care and support in minority ethnic communities: A survey of Danish primary care dementia coordinators. *Dementia*. 19(8):2702-2713.

ENDS

Appendix 3 • Indicative survey questions WP1a.

DiSCOVERY WP1a. Recovery College Indicative Survey Questions *draft v0.1*

Highlighted questions in green are those asked during the early scoping survey in 2019²⁹

Covering email/social media text

We would like to find out which Recovery Colleges are offering, or linking with other providers of courses about dementia in Recovery Colleges, as part of a UK-wide funded research project.

We would be very grateful if you could take the time to complete a survey. It should take no more than xx minutes. Depending on your responses, you may be asked to complete xx questions across xx sections. Nearly all questions have quick click yes/no options, but we have also included free text boxes for you to leave any thoughts as you go along.

It is possible that your memory service and local Recovery College may be quite separate, or staff from your memory service may be doing occasional Recovery College sessions on specific things – which means you may find yourself clicking a lot of ‘don’t know’ answers. Please don’t think the survey isn’t relevant to you - it’s ok not to know as we are interested in these things too!

All data will initially be held by SurveyMonkey®. Data will then be collated and used by Norfolk and Suffolk NHS Foundation Trust to understand and report on the current Recovery College dementia courses in the UK. You do not need to enter any identifying details unless you wish to be contacted further. If you do choose to enter your details, your data will still be reported on anonymously. Please do not write any identifiable/personal information about your team, service users or colleagues.

The survey link can be found here: xx. The survey will be open for responses until xx.

Thank you very much for your time and valued contribution.

DiSCOVERY research team

Section 1 Background

How did your Recovery College first start? Free text

Who is your Recovery College open to? Drop down options

Is your Recovery College affiliated with/run by an NHS Trust? Yes/No

If yes: Please briefly describe how the Recovery College fits within the Trust, structurally-speaking.
Free text

How is your Recovery College commissioned? Free text

Does your Recovery College currently run any courses about dementia? Yes/No/Don’t know

Has your Recovery College previously run courses about dementia? Yes/No/Don’t know

Why did they discontinue? Free text

Does your Recovery College plan to start running courses about dementia? Yes/No/Don’t know

Section 2 Dementia course access and characteristics

What is the name given to the dementia course? Don’t know/Free text

How long have dementia courses been running in your Recovery College? Drop down

- Less than a year
- 1-2 years
- More than 2 years

How did the course come about? Free text

What are the key topics/content that the course covers? Free text

How have you developed your dementia course content? Please select all appropriate options.

- Using local or national guidelines
- Using research publications
- Adopting a course programme from another site
- In collaboration with people with dementia
- In collaboration with family or friends supporting people with dementia
- In collaboration with academic staff
- In collaboration with NHS staff
- Using materials produced by dementia charities
- Other (please specify)

How frequently is the course delivered? Drop-down

Over how many days/sessions? Free text

How long is each session? Drop-down

Who are the dementia courses delivered by? Please select all appropriate options.

- People with dementia
- Family or friend supporters
- Staff working within an NHS Trust
- Staff working at another organisation
- Other (please specify)

Where is the course held? Free text

Is there support for people to access the course? Yes/No

If yes, please provide details on the type of support offered (e.g., transport?) Drop-down/Free text

Are there non-dementia-specific courses that you recommend to students of dementia-specific courses? Free text

Are non-dementia courses technically open to people using dementia services? Yes/No

Who is able to attend your dementia courses? Please select all appropriate options.

- People with dementia
- Family/friend supporters
- NHS Trust staff
- Staff working at other organisations (please specify)
- Other (please specify)

Thinking of the last course that ran, how many people accessed the course? Drop-down/Don't know

- Overall
- People with dementia
- Family or friend supporters
- Staff

Thinking of the last dementia course that ran, what was the group size? Drop-down/Don't know

Who generally accesses the course? Drop down options: people with dementia, family or friend supporters, people with mild cognitive impairment, staff, further drop-down options for type of staff

What is the balance of staff/people with dementia family or friend supporters? Drop-down/Don't know

Do people with dementia generally attend with a family or friend supporter? Yes/No/Don't know

What is the relationship of the family or friend supporters to the people with dementia? Drop down: family [if so, how are they related?], friend

Do family or friend supporters attend alone? Yes/No/Don't know

Do the people who attend normally have a formal diagnosis of dementia? Yes/No/Don't know

On average, what percentage of attendees are people with dementia? Drop down

On average, what percentage of attendees are family or friend supporters? Drop down

On average, what percentage of attendees are staff? Drop down

What kind of staff normally attend? Drop down

Which services are they from? Drop down
 What kind of role do they have? Drop down

Section 3 Impact of the COVID-19 pandemic

PRIOR to the onset of the COVID-19 pandemic i.e. from a face-to-face course delivery context:

How frequently was the course delivered? Free text

How many sessions were there? Drop down

How long did each session last? Drop down

Who were the dementia courses delivered by? Please select all appropriate options.

- People with dementia
- Family/friends supporting people with dementia
- Staff working within your NHS Trust
- Staff working at another organisation
- Other (please specify)

Where was the course held? Drop down NHS site/non-NHS site

What accessibility support was there for people to access the course? Please provide details on the type of support offered e.g., transport/written materials Free text

Has COVID-19 impacted the delivery of your (dementia) courses? Yes/No

What changes (if any) have you made to the course as a result of the pandemic? Free text

Has the content changed as a result of COVID-19? Yes/No

(If you continued to run courses) Did COVID-19 impact the number of people with dementia/supporters who attended? Yes – decreased/Yes - increased/No/Don't know

Have you noticed a difference in the demographics of the people attending courses since COVID-19, for example..? Yes/No/Don't know

If your course uses co-production/co-delivery, did you continue this throughout the pandemic? Yes/No

Are you now offering face-to-face courses (or blended learning)?/How is the course currently delivered? Yes/No/Free text

If online:

Have you offered any support to help people to attend online courses? Yes/No/Don't know

Do you send out materials via email/online? Yes/No/Don't know

Do you think that people have engaged as fully with the online content as they did with face-to-face learning? Yes/No/Don't know

Have you included any features to encourage engagement e.g., use of breakout rooms, chat function? Yes/No/Don't know

Has this worked well? Yes/No/Don't know/Free text

Do you think online delivery has been as successful as running courses face-to-face? Yes/No/Don't know

If yes, why? Free text

If no, why not? Free text

Other demographics

Thinking about the last dementia course that you ran, please consider the following:

Age roughly what is the average age of the attendees of the dementia course/what percentage of attendees fit into each of these categories? Drop down number/range options. 18-35, 36-45, 46-55, 56-65, 66-75, 76+

Sex/Gender roughly what percentage of attendees are male/female? Drop down

% Men % Women

Ethnicity

Roughly what percentage of attendees fit into each of these ethnic groups? Asian/Asian British, Black/Black British, Mixed-Multi Ethnicity, Roma/Gypsy/Traveller, White non-British, Other.

Do you feel the ethnicity mix of attendees/service users accurately reflects your local area? Yes/No

Cultural background

What percentage of your attendees were not from a British cultural background? i.e. not born in the UK or raised in another country etc.

Socioeconomic indicators

Thinking about the wider population and area that your Recovery College/service serves, assess to what extent your population represents:

Rural > Urban scale (Very rural > very urban)

Deprived > Affluent Scale (Neighbourhood level, very deprived > very affluent) or

Average socioeconomic status of service users/attendees (High, Middle, Low)

Co-producing and co-delivering dementia courses

Do you have peer tutors who co-deliver the dementia course? Yes/No

If no, why not? Free text

How many peer tutors do you have? Drop down

Are these people with dementia, family or friend supporters, or both? Drop down

How did people become peer tutors? Free text

Have there been benefits of including peer tutors? Yes/No/Don't know

If yes, what have these been? Free text

Have there been any difficulties? Yes/No/Don't know

If yes, what have these been? Free text

Was the course co-designed? Yes/No/Don't know

Again, positives/difficulties of this process? Free text

Impact of the dementia course

Do you collect feedback from your dementia course attendees? Yes/No/Don't know

If yes: What questions do you ask? Free text

Is there anything about the course that has been particularly successful? (This could be related to format, content, tutors etc) Free text

Are there any aspects that have been less successfully received? Free text

Have you formally evaluated the course? Yes/No/Don't know

If yes: Please provide a brief explanation of the outcomes used as part of this evaluation. Free text

Are any reports or publications available? Yes/No/Don't know If yes:

Would you be able and willing to share these with us? Yes/No

What do you think is important to consider when evaluating the impact of the courses? How do we know if the course has had a meaningful and positive impact on attendees? Free text

Links between your Recovery College and memory service/s

What country are you in? Free text

What county/counties/metropolitan area are you in? Free text

Do you consider the dementia course to be integrated within the post-diagnostic dementia support services? Yes/No/Don't know

What else is available for people after a diagnosis of dementia in your area/Trust and what does the Recovery College course add that's different? Free text

How do dementia-specific courses compare to/complement other (Trust-wide) non-recovery-college dementia courses or post-diagnostic support that the Trust provides? Free text

What are the links between these services and what order do people access them? For example, do Recovery Colleges refer people with dementia on to other services after the course has ended? Free text

How do people find out about the dementia course? Drop down

How are they offered/signposted? Drop down

Do people select courses themselves? Yes/No/Don't know

Are there any differences in the way that staff/ people with dementia/family or friend supporters access the course? Yes/No/Don't know/Free text

Please rate the strength of the relationship between your memory service and Recovery College.
Likert scale

Thank you for your time and contribution. If you would like to see the results of the survey, please leave your name and email address here - contact details box. For all other news relating to the DiSCOVERY study, please visit our webpage xx or follow us on Twitter at NSFT Research xx

DiSCOVERY WP1a. Memory Services Indicative Survey Questions *draft v0.1*

Similar covering email/social media text as Recovery College survey above

Section 1 Background

Does your service guide people to Recovery College courses as a method of post-diagnostic support?
Yes/No/Don't know/Free text

Does your memory services team use the term 'recovery' in relation to people with dementia? Yes/No /Don't know/Free text

Are any staff in your service currently running any courses or sessions about dementia in your local Recovery College? Yes/No/Don't know/Free text

Have any of your staff previously run Recovery College courses or sessions about dementia? Yes/No /Don't know/Free text

Does your memory service plan to start running courses about dementia within the local Recovery College? Yes/No/Don't know/Free text

Are there non-dementia-specific courses run by your local Recovery College that your service recommends to people with dementia who access your memory service? Yes/No/Don't know/Free text

Are non-dementia courses technically open to people using dementia services? Yes/No/Don't know/Free text

What do you understand by the word 'recovery' in dementia - Don't know/Free text

When do you think the term 'recovery' should be used in dementia services - Don't know/Free text

How would you explain to people with dementia and families the work of a Recovery College?
Don't/know /Free text

Other sections - content expected to be the same as the Recovery College survey

Links between your memory service and the Recovery College

What country are you in? Free text

What county/counties/metropolitan area are you in? Free text

Do you consider the dementia course to be integrated within the your local Recovery College service? Yes/No/Don't know/Free text

Is the dementia course seen by you as part of post-diagnostic support services? Yes/No/Don't know

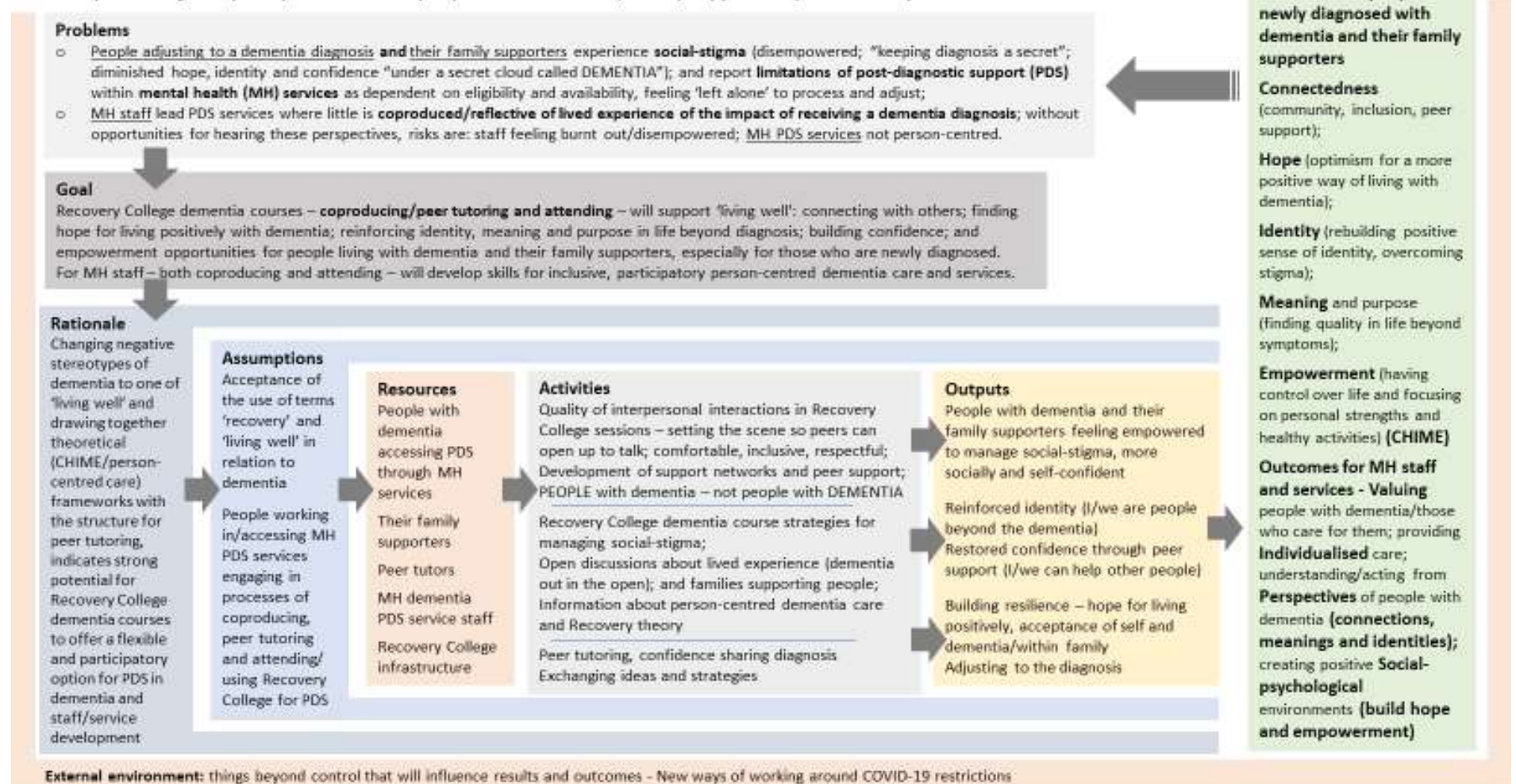
How do dementia-specific courses compare to/complement other (Trust-wide) non-Recovery College dementia courses or post-diagnostic support that the Trust or other local services provide that you might refer people to? Free text

Please rate the strength of the relationship between your memory service and Recovery College.
Likert scale

Thank you for your time and contribution. If you would like to see the results of the survey, please leave your name and email address here - contact details box. For all other news relating to the DiSCOVERY study, please visit our webpage xx or follow us on Twitter at NSFT Research xx

Appendix 6 • Theory of Change map

Theory of Change map - coproduced with people with dementia, family supporters (PPI advisors) and mental health service staff



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