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

Submission date
15/03/2022

Recruitment status
No longer recruiting

Registration date
12/04/2022

Overall study status
Completed

Last Edited
03/08/2023

Condition category
Mental and Behavioural Disorders

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol

Background and study aims
Receiving a diagnosis of dementia is life-changing for the person and their family. Lots of factors can affect the quality of support post-diagnosis.

Mental health trusts have adopted Recovery Colleges to support 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 (co-produce), alongside staff members. Some Recovery Colleges across England offer courses with/for people with dementia.

We want to understand how, following diagnosis of dementia, Recovery Colleges can help people. We want to find out what attending, co-designing, and co-running courses is like for people with dementia, families, and staff. We also want to know how people who access NHS memory services find out about these courses.

Who can participate?
Patients and staff in recovery colleges in the UK

What does the study involve?
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.

We will visit different dementia courses and interview people. We will discuss this information with everyone involved to reflect real life. We will use this updated theory to co-produce guidance and resources for UK Recovery Colleges.

What are the possible benefits and risks of participating?
Benefits - Previous work has shown that people with dementia often enjoy speaking about their experiences, as this can prompt feelings of inclusion and personhood. Similarly, family supporters of people with dementia can derive benefit from talking about their life with their loved one with someone independent from the situation. It is also hoped that staff will find participating a fulfilling and enjoyable experience, and that they will be able to see how their

involvement might contribute to improved quality of care for people with dementia. Members of the advisory groups will be reimbursed for their time and any expenses they incur.
Risks - There is little foreseeable risk to participants during the course of the study. However, if during PPI groups, a person indicates a need related to their dementia, information about appropriate local support will be provided.

Where is the study run from?
Norfolk and Suffolk NHS Foundation Trust (UK)

When is the study starting and how long is it expected to run for?
January 2022 to December 2024

Who is funding the study?
National Institute for Health Research (NIHR) (UK).

Who is the main contact?
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Contact information

Type(s)
Principal investigator

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
309761, 315262

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
CPMS 51743, NIHR131676, IRAS 309761, IRAS 315262

Study information

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

Acronym
DiSCOVERY

Study objectives
Current hypothesis as of 01/08/2023:
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 family/friend supporters and staff.

Previous hypothesis:
We aim to develop an initial realist programme theory, based in evidence, to explain how Recovery College dementia courses and post-diagnostic support lead to intended and unintended outcomes for people with dementia, their supporters, and staff. Towards the end of the study, this theory will be used to co-produce guidance and resources for implementing Recovery College dementia courses as a form of post-diagnostic support.

Ethics approval required
Old ethics approval format

Ethics approval(s)
1. DiSCOVERY WP1 approved 09/03/2022, West Midlands - Coventry & Warwickshire Research Ethics Committee (The Old Chapel, Royal Standard Place, Nottingham, NG1 6FS, UK; +44 207 104 8013; coventryandwarwick.rec@hra.nhs.uk), ref: 22/WM/0021
2. DiSCOVERY WP2-4 approved 27/10/2022, West Midlands - Coventry & Warwickshire Research Ethics Committee (The Old Chapel, Royal Standard Place, Nottingham, NG1 6FS, United Kingdom; +44 207 104 8013; coventryandwarwick.rec@hra.nhs.uk), ref: 22/WM/0215

Study design
Observational qualitative

Primary study design
Observational

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Dementia support

Interventions

Current intervention as of 01/08/2023:
Work Package 1 builds an initial understanding (Initial Programme Theory) of Recovery College dementia courses in the UK through a rapid realist review, a staff survey and discussions with Patient & Public Involvement (PPI) and staff advisory groups. Data analysis and theory building is an iterative process using realist principles and methods throughout.

Work Package 2 involves recruiting participants to a realist evaluation of post-diagnosis Recovery College dementia courses within 5 case studies, where we refine and test the initial programme theory developed in Work Package 1 by incorporating qualitative data from five embedded case studies, and deliberating further with the PPI and staff advisory groups.

Work Package 3 is a scoping review where we will review domains of outcome - potential impacts of attending recovery focused dementia courses - emerging from the programme theory, and draw on literature to select measures that align with these outcomes. These will be reviewed and discussed with PPI and staff advisors to
create a 'library' of outcome measures as resources for people to use to evaluate the impact of Recovery College dementia courses.

Work Package 4 involves co-producing with PPI and staff advisors accessible resources of 'what works', to support planning, co-production, implementation and evaluation of Recovery College dementia courses, and sharing these with knowledge users from memory services and Recovery Colleges, and the public.

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Previous intervention:
WP1 can be broken down into 3 main stages. In WP1a we aim to gain an understanding of the post-diagnostic support currently offered by the NHS. This will be achieved via survey/s, which will also be utilised to invite/recruit staff to express interest in and form the staff stakeholder advisory group. WP1b involves the development of an initial programme theory and rapid realist literature review. The programme theory will be used to identify potential explanatory mechanisms to explain how and why Recovery Colleges might help people with dementia and their supporters to adjust to their diagnosis. In WP1c, this information will be discussed and deliberated with two stakeholder advisory groups (patient and public involvement [PPI] and staff), to refine the theory in line with peoples' lived experiences.

The details of each stage are outlined below.

WP1a: Mixed methods survey (MONTHS 1-6)
During this stage, we will build on initial scoping survey work that has previously been carried out, by designing and piloting a survey to be sent to Recovery Colleges and associated memory services across the UK. For Recovery Colleges, we will seek to understand more about any dementia courses they offer. Questions will ask about course content and delivery, challenges and successes, changes that have been made as a result of COVID-19, as well as the links between Recovery Colleges and memory services.

This survey/s will also be used to inform site selection for WP2. Surveys will be distributed electronically (via email and/or social media). The survey will be designed and piloted over the first 2 months of the study (1-2), then a final version will be sent out and the results analysed over the following 4 months (3-6).

WP1b: Rapid realist review (MONTHS 1-6)
The output of this stage will be an initial programme theory, which will be developed with input from stakeholder advisory groups (see WP1c for details of this process). The review will involve the synthesis of evidence from a number of different sources and will consist of 5 stages:
1) The project team will hold 1-2 half-day meetings to discuss and develop an initial programme theory around Recovery College dementia course planning, delivery and outcomes.
2) A search strategy will be created to explore the literature. This will cover online databases (such as PsycINFO, CINAHL) and other relevant websites, including grey literature. Once the searches have been run, results will be downloaded into reference management software and subjected to 2 rounds of screening: first by title and abstract, then full text. All records will be screened by one researcher and another researcher will screen a 10% sample to check for errors. They will be looking for material that i) relates to Recovery Colleges/recovery approaches; ii) is delivered in the NHS and; iii) contains relevant empirical data and/or theory. The results of this stage will be used to refine the initial programme theory described in stage 1.
3) One researcher will assess the selected documents for relevance (are sections of text within this document relevant to programme theory development?) and rigour (Are these data sufficiently trustworthy to contribute to programme theory development?).
4) One researcher will extract data. This will include descriptive data describing the included documents (e.g., date, type of document, study design, etc.) and extracts of relevant data from full text documents. These extracts will be uploaded to NVivo (qualitative data analysis software). Another researcher will assess 10% of the records for errors.
5) The data will be analysed and synthesised, using a realist logic of analysis to explain potential context-mechanism outcome configurations. These will help us to understand when, why and how Recovery College dementia courses may lead to certain outcomes.

WP1c: Stakeholder advisory groups consultation and deliberation (MONTHS 2-6)
The stakeholder group meetings will be held online (over Zoom or MS Teams) as a result of the pandemic. As described previously, two groups will be set up: one for staff working in NHS memory services, and another for people with dementia and their family/friend supporters who have attended or co-produced Recovery College courses. These groups will be consulted throughout the course of the entire study but only their input to WP1 is described here.

Two two-hour consultation meetings will be held to discuss the findings that emerge from the rapid realist review (WP1b). To ensure as many people as possible can attend, both groups (PPI and staff) will be invited to both meetings. The two groups will be conducted at different days and times (i.e., morning/afternoon) within the same week, as another method of enabling attendance.

The groups will be facilitated by members of the study team who have experience working with people with dementia and/or in NHS services. The initial programme theory will be presented to groups in an accessible and understandable way e.g., using vignettes. Group members will be asked to provide their thoughts and opinions on the findings so far. Groups will be split into breakout rooms of up to 6 people to facilitate discussion. These groups will consist of either staff or people with dementia and carers, to ensure people feel comfortable during the discussion. The facilitators will take notes of the discussion, which will also be recorded. These records will be used to assess whether the groups' experiences fit with the initial programme theory, and whether any changes need to be made in order to reflect these.

If people are unable to attend the groups, they will be able to contribute in another way e.g., via one-to-one phone call, meeting, or email.

Intervention Type

Behavioural

Primary outcome(s)
The question of 'How can Recovery Colleges dementia courses be used as a form of post-diagnostic support?' will be assessed using stakeholder group meetings over the course of the study, analysed using initial realist programme theory

Key secondary outcome(s))
There are no secondary outcome measures

Completion date
31/12/2024

Eligibility

Key inclusion criteria
1. Survey: Any Recovery Colleges and statutory Memory Services in the UK
2. PPI group: People with dementia; family/friend supporters
3. Staff group: Psychiatrists, community mental health nurses including independent nurse prescribers, clinical psychologists, occupational therapists, social workers and assistant practitioners/community support workers

Participant type(s)
Patient, Health professional, Carer, Other

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Key exclusion criteria
PPI/Staff members that do not meet the inclusion criteria

Date of first enrolment
01/04/2022

Date of final enrolment
31/08/2022

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Hellesdon Hospital
Drayton High Road
Norwich
United Kingdom
NR6 5BE

Sponsor information

Organisation
Norfolk and Suffolk NHS Foundation Trust

ROR
https://ror.org/03400ft78

Funder(s)

Funder type
Government

Funder Name
NIHR Evaluation, Trials and Studies Co-ordinating Centre (NETSCC)

Funder Name
National Institute for Health Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan

The current data sharing plans for this study are unknown and will be available at a later date

IPD sharing plan summary

Data sharing statement to be made available at a later date

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
HRA research summary			28/06/2023	No	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes