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Exploring the potential for ENGAGE-PD physical activity coaching in the NHS for people newly diagnosed with Parkinson’s: perspectives of people with lived experience of Parkinson’s

Submission date 19/08/2025	**Recruitment status** No longer recruiting	☐ Prospectively registered ☐ Protocol
Registration date 11/11/2025	**Overall study status** Completed	☐ Statistical analysis plan ☐ Results
Last Edited 11/11/2025	**Condition category** Nervous System Diseases	☐ Individual participant data [X] Record updated in last year

Plain English summary of protocol

Background and study aims

Parkinson’s is the fastest-growing neurological condition in the world. It is predicted that one in 37 people alive today will be diagnosed with Parkinson’s. It can affect mobility and independence. Worldwide research suggests that physical activity can slow Parkinson's progression, yet people with Parkinson's are often less active than their peers.

This study aims to find out if ENGAGE-PD, which provides personalised, therapist-led coaching support, could help people recently diagnosed with Parkinson's in UK NHS rehabilitation settings. ENGAGE-PD was originally developed in the USA. There are three main elements:

1. Physical activity coaching
2. A physical activity workbook
3. Physical activity monitoring

The researchers will consult people with lived experience of Parkinson’s in the UK to help design a UK version of ENGAGE-PD.

Who can participate?

People aged 18 years or over, able to provide informed consent, with a confirmed diagnosis of Parkinson’s, or care partners of people with Parkinson’s

What does the study involve?

With participants' permission, the researchers will share their ideas through a secure website or by post. Through a series of stages, agreement will be reached by using ‘Group Concept Mapping’ to prioritise the elements relevant to a UK trial. Participants will complete a questionnaire that asks for some basic information about them. This will be anonymised (identifiable information removed) so that researchers can make sure they are including the views of people from different groups. Participants can receive payment in the form of cash or a voucher to recognise the time taken for each stage of the study.

What are the possible benefits and risks of participating?
There is a minor financial benefit to taking part. Participants will be providing information on what should be included in a UK version of the ENGAGE-PD intervention to help people with newly diagnosed Parkinson's with their physical activity levels. The knowledge gained from this study may help people recently diagnosed with Parkinson's and the NHS services that support them. A future UK version of ENGAGE-PD could help service users to maintain activity levels, independence, and self-management of their Parkinson's. All participants will be provided with a summary of the study findings and can choose to be contacted with updates on future related research progress. The main disadvantage of taking part is giving up time to take part in the study, but each stage can be completed at a time convenient for participants.

Where is the study run from?
University of Plymouth (UK)

When is the study starting and how long is it expected to run for?
May to December 2025

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

Who is the main contact?
Jonathan Gilby, jonathan.gilby@postgrad.plymouth.ac.uk

Contact information

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Public, Principal investigator

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Protocol serial number
6213, NIHR 305241

Study information

Scientific Title
Exploring ENGAGE-PD physical activity coaching in the NHS for people newly diagnosed with Parkinson’s: perspectives of people with lived experience of Parkinson’s using Group Concept Mapping

Study objectives
The aim is to use the Group Concept Mapping (GCM) method with people with lived experience of Parkinson’s to gain consensus on what are the most important aspects of a UK version of ENGAGE PD to be trialled in UK NHS Rehabilitation settings in a future feasibility trial.

GCM results in a stakeholder-authored visual map of the ideas that are important to the group. This will inform planning and evaluation of a UK version of the UK ENGAGE-PD participant workbook.

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 23/05/2025, University of Plymouth, Faculty of Health and Human Sciences Faculty Research Ethics and Integrity Committee (School of Health Professions, Faculty of Health and Human Sciences InterCity Place, Plymouth Railway Station, North Road East, Plymouth, PL4 6AB, United Kingdom; +44 (0)1752600600; Research.Ethics@plymouth.ac.uk), ref: 6213

Study design

Participatory mixed-methods

Primary study design
Observational

Study type(s)
Other

Health condition(s) or problem(s) studied
Parkinson's disease

Interventions
The first stage in developing a UK version of the ENGAGE-PD physical activity coaching intervention to test in a future feasibility trial is consulting with people with lived experience of Parkinson’s. ‘Group Concept Mapping’ (GCM) is a consensus approach involving qualitative and quantitative methods in a structured, sequential process to organise the ideas of a group. It creates stakeholder-authored visual representations of ideas, using multi-dimensional scaling to produce maps to guide planning and evaluation efforts on issues that matter to the group. The structured consensus-building approach limits peer pressure and suppressing of the voices of less-dominant participants. It has been successfully used to engage people with Parkinson’s and hard-to-reach populations in research.

Participants will be sent a ‘focus prompt' to direct their thinking towards important things to engage people who have recently been diagnosed with Parkinson's in physical activity. The focus prompt will be pilot tested with the Project Advisory Group (PAG). All the ideas generated will be sorted and rated for what the group consider to be the most important and realistic aspects to include in an intervention to support people with newly diagnosed Parkinson's to engage in physical activity in the UK NHS rehabilitation settings.

Three GCM stages will be delivered and data collected using the online ‘groupwisdom™’ secure web application (with an option for paper data collection via post if requested). (‘Brainstorming’, ‘sorting’ and ‘rating’). Training and support will be provided to set up an account on the ‘groupwisdom™’ web application, which will be used to collect, organise, prioritise, and analyse data. It can also support participants throughout the GCM stages with online training resources, including an introductory tutorial for each stage to support participants. Each stage will be open for at least 2 weeks with each stage requiring approximately 2 hours of participants’ time. GCM uses multivariate statistical analysis of the information from stages one to three to represent the ideas of the group in two-dimensional concept maps.

Participant demographic data will be collected for equality, diversity, and inclusion considerations. Anonymised information will be presented using descriptive statistics (without showing detailed information of sub-groups of less than five participants to reduce the risk of participant identification).

The information gained from the first three stages of GCM will inform the co-design with the PAG of a UK version of the ENGAGE-PD physical activity coaching intervention.

Intervention Type
Other

Primary outcome(s)

Likert ratings for the Importance and Feasibility of each idea generated by the group will be collected at the rating stage of the project (weeks 6 to 8) in the following format: On a scale of 1 to 4, please rate how relatively important you think each idea is to engage people newly diagnosed with physical activity: 1 = relatively unimportant, 2 = slightly important, 3 = moderately important, 4 = very/extremely important. On a scale of 1 to 4, please rate how realistic you think it is for each idea to be included in National Health Service rehabilitation: 1 =relatively unrealistic, 2 =slightly realistic, 3 = moderately realistic, 4 = very/extremely realistic.

Key secondary outcome(s))

Participant demographic information for subgroup analysis will be collected from an anonymous participant questionnaire in week 1 of study data collection

Completion date

31/12/2025

Eligibility

Key inclusion criteria

1. Adults aged 18 years or over
2. Lived experience of Parkinson’s: at least 75% of participants with a neurologist-confirmed diagnosis of idiopathic Parkinson’s. The aim is that half of the PwP will be within 5 years of diagnosis to support recall of relevant lived experience. Up to 25% of the overall sample can be Parkinson’s care partners.
3. Participants able to provide informed consent and, either independently or with the assistance of an appropriate care partner, review English-language study paperwork and fill in questionnaires (although budget is available for translation of resources into one other language)

Participant type(s)

Carer, Patient

Healthy volunteers allowed

No

Age group

Adult

Lower age limit

18 years

Sex

All

Key exclusion criteria

1. People or care partners of people without a confirmed idiopathic Parkinson’s diagnosis
2. People without capacity to provide informed consent.

Date of first enrolment

17/06/2025

Date of final enrolment
22/08/2025

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University of Plymouth
Drake Circus
Plymouth
United Kingdom
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Sponsor information

Organisation
University of Plymouth

ROR
https://ror.org/008n7pv89

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care 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 datasets generated during the current study will be available upon request from Jonathan Gilby (jonathan.gilby@postgrad.plymouth.ac.uk)

IPD sharing plan summary
Available on request