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Co-designing system improvement for Atypical Parkinsonian Syndromes

Submission date
02/09/2025

Registration date
10/10/2025

Last Edited
28/04/2026

Recruitment status
Recruiting

Overall study status
Ongoing

Condition category
Nervous System Diseases

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

Plain English summary of protocol

Background and study aims
People living with Atypical Parkinsonian Syndromes (APS) often experience complex symptoms that affect movement, thinking, mood, vision, eating, and communication. These individuals quickly become reliant on family and carers and require specialised clinical care to maintain their quality of life and avoid unnecessary hospital admissions. However, access to services varies significantly across the UK, leading to inequalities in care. This study aims to understand what aspects of current health and social care provision influence these inequalities, how service configuration affects people's ability to live well with APS, and how care can be improved within the existing system.

Who can participate?
1. People living with APS
2. Carers of people with APS
3. Health, social care and voluntary organisation professionals involved in supporting people with APS

What does the study involve?
The study will:
1. Review policies, guidelines, and services relevant to people with APS (a realist review).
2. Interview people with APS and their carers about their experiences accessing and navigating services.
3. Speak to professionals about the challenges of delivering care.
4. Map networks and services available in different locations, using a system design approach.
5. Hold two workshops with participants and collaborators to explore solutions and co-design a questionnaire for future research.
6. In the long term, develop a new model of care based on findings, to inform a follow-on evaluation of practical strategies.

What are the possible benefits and risks of participating?
Benefits:
1. Participants can contribute to improving services for people with APS.
2. Carers and patients can share their experiences to help influence positive change.

3. Professionals may help identify and remove barriers in care provision.
Risks:
1. Discussing personal experiences may be emotionally challenging.
2. Time commitment may be a burden for some participants.

Where is the study run from?
University Hospital Southampton NHS Foundation Trust (UK)

When is the study starting and how long is it expected to run for?
March 2026 to February 2027

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

Who is the main contact?
Dr Annalisa Casarin, annalisa.casarin@nihr.ac.uk

Contact information

Type(s)
Public, Scientific, Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
347277

Central Portfolio Management System (CPMS)
63912

National Institute for Health and Care Research (NIHR)
207984

Protocol serial number

Study information

Scientific Title
Co-designing improvements to systems of care and support to tackle inequality of access for people with Atypical Parkinsonian Syndromes: combining a system approach and realist review to inform a discrete choice experiment

Acronym
Improve APS

Study objectives
Aims:
1. To explore the diversity of experiences that people with APS and their carers have with access and use of health and care services, understanding the context and complexity of provision in specific locations in England
2. To co-design system improvement recommendations based on available assets that can address people's needs and preference, reduce disparities, and improve the responsiveness of health and social care in providing coordinated services

This will be achieved by:
1. Building programme theories of what works, for whom and why using realist methodology
2. Asking people affected to share their experience of access and navigation of the current system to create a map of networks and services, guided by the Engineering Better Care system design toolkit
3. Understanding the current system strengths and involve service users and providers to create a questionnaire for a follow-up study using a Discrete Choice Experiment approach
4. To disseminate results co-creating material with public contributors

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 28/11/2025, Wales REC 6 (Health and Care Research Wales, Floor 4, Crown Building, Cardiff, -CF10 3NQ, United Kingdom; +44 (0)2922940911, +44 (0)2922 940954, +44 (0)2922 941090; Wales.REC6@wales.nhs.uk), ref: 25/WA/0299

Study design
Mixed methods, realist review (qualitative), system thinking, discreet choice experiment (quantitative)

Primary study design
Observational

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Atypical Parkinsonian Syndromes

Interventions
The project will be conducted over 24 months. It combines realist methodology with an engineering-informed systems approach to understand the factors affecting the provision of care and support to people affected by APS. This approach will enable us to understand what works, for whom and why in six areas of England. Exploration of inequalities of access will provide the knowledge base for a future preparation and evaluation of system improvement guidance.

Intervention Type
Other

Primary outcome(s)
Diversity of experience measured using interviews and thematic analysis at baseline

Key secondary outcome(s))
Health and social care service utilization, informal care, accommodation and living situation, employment and productivity, education measured using the Client Service Receipt Inventory domains at baseline

Completion date
28/02/2027

Eligibility

Key inclusion criteria
1. People with mental capacity and ability to communicate.
2. People providing consent to participate of all genders, age, ethnicity, socio economic background, location.

Patients' cohort:
People with mental capacity (according to carer/family) and ability to communicate, affected by APS, selected at different stages:
1. People at a moderate stage of the APS disease, 2-3 years from diagnosis, to capture information regarding diagnosis and initial care and referrals, and to obtain their views while still able to communicate.
2. People at later stage of the APS disease, >3 years.

Carers' cohort:
1. Defined as someone who cares for, supports or provides help to someone affected by APS, either family member, relative, paid carer, close friend or neighbour on a regular basis for at least 2 years.
2. Carers of deceased people (<1 year to avoid recall bias) in order to capture information about the majority of the pathway through the care system.
3. Carers able to represent their relative/employer and consenting to also share their own experience of caring for people with APS.

Health care, social care and charity staff cohort:
Staff with or without experience of liaising with people affected by APS, but aware of barriers and facilitators of access to services for people with APS.

Participant type(s)

Carer, Health professional, Patient

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 years

Upper age limit
100 years

Sex
All

Total final enrolment
0

Key exclusion criteria
1. People with multi-morbidities that affect function (mild cognitive impairment, dementia, speech and language impairment, frailty), other conditions that would prevent participations to the study.
2. People who refuse consent after initial meeting or during the study.

Date of first enrolment
16/02/2026

Date of final enrolment
31/12/2026

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University Hospital Southampton NHS Foundation Trust
Southampton General Hospital
Tremona Road
Southampton
England
SO16 6YD

Sponsor information

Organisation
University Hospital Southampton NHS Foundation Trust

ROR
https://ror.org/0485axj58

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
Transcripts of interviews/focus groups and qualitative data analysis: when data collection is completed, these will be stored on encrypted files located in the sponsor servers, plus will be made available (to be explored further) as requested by the funder, e.g., through online open access repository. They will be anonymised and made available, with consent by study participants.

IPD sharing plan summary
Stored in publicly available repository

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?

Protocol (other)	Protocol for realist review	12/12/2025	28/01/2026	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes