Casarin A et al, 2026, Co-designing improvements to systems of care and support to tackle inequality of access for people with Atypical Parkinsonian Syndromes.. International Journal of Integrated Care 26(S2):394 DOI: doi.org/10.5334/ijic.ICIC26394

POSTER ABSTRACT

Co-designing improvements to systems of care and support to tackle inequality of access for people with Atypical Parkinsonian Syndromes.

International Conference on Integrated Care (ICIC26), Birmingham, 13-15 April 2026

Annalisa Casarin[1], Boyd Ghosh[2]

1: University Of Hertfordshire, United Kingdom
2: University Hospital Southampton NHS Foundation Trust, United Kingdom

Around 15,000 people in the UK live with Atypical Parkinsonian Syndromes (APS). Unlike typical Parkinson's disease, APS includes rare and complex conditions such as Corticobasal Degeneration (CBD), Multiple System Atrophy (MSA), and Progressive Supranuclear Palsy (PSP). These illnesses go beyond tremors or slowed movement; they affect balance, thinking, mood, speech, swallowing, and even vision. The conditions progress rapidly, and individuals often become dependent on family members or carers within a short time. As their needs grow, so does the importance of timely, specialist, and coordinated care.

Unfortunately, many families report having to battle for basic support, with long delays, misdiagnoses, and limited awareness among health and social care professionals. Services vary dramatically across regions, leading to stark inequalities. This inconsistency is not only distressing for patients and carers—it's costly for the healthcare system. The Improve APS study, led by researchers and shaped by those with lived experience, seeks to understand why people with APS aren't getting the care they need.

The study adopts a realist methodology embedded in a system approach, which will provide greater explanatory evidence as to why particular patient groups struggle to access services that meet their health and social care needs. Starting with formulation of the Initial Programme Theories (phase 1), from published literature and knowledge within the project team, we will test these theories through interviews and focus groups with stakeholders who use, work in and commission services for people with APS (phase 2).

Researchers will speak with 24 individuals living with APS and their carers to hear about their journeys: the barriers they've faced, the services they've used (or couldn't access), and what helped or hindered their ability to live well with their condition. Around 30 Health and Social care professionals will also be interviewed to understand the pressures and constraints they face in trying to deliver appropriate care. The result will be a "system map"—a visual representation of the networks, services, and support systems that people with APS have (or don't have) access to in different areas. The research team will then bring together participants, carers, clinicians, and

service designers in two collaborative workshops. These sessions will explore potential solutions, drawn from the best examples found across the country. The team will then use these ideas to design a questionnaire (to run a Discrete Choice Experiment. Phase 3) to ask people affected by APS what they prefer—ensuring that the voices of a broader and more diverse group are heard before any national recommendations are made. Exploration of inequalities of access will provide the knowledge base for a future preparation, implementation and evaluation of system improvement guidance.

We aim to bring early results to the conference, sharing insights from the realist and qualitative phases of the study.