ImproveAPS Study Newsletter

University of Hertfordshire UH

NHS University Hospital Southampton NHS Foundation Trust

The ImproveAPS Study is a research project funded by the National Institute for Health and Care Research (NIHR). Original title: "Co-designing improvements to systems of care and support to tackle inequality of access for people with Atypical Parkinsonian Syndromes". It started in March 2025. This newsletter brings a study update.

Issue 3. November 2026

Project update

Conversations with people with Atypical Parkinsonian Syndromes (APS) and their carers

The project has successfully recruited **36 participants across 30 cases,** involving people with APS and their carers. These participants are based across England, from Cornwall to Tyne and Wear, and live in areas ranging from some of the most deprived to some of the most affluent communities in the country. Participants lived between 3 and 101 miles from their nearest specialist centre, giving us insight into a wide range of experiences of accessing care and support.

Analysis of the first 16 cases suggests that one of the biggest challenges is not necessarily whether services exist, but whether people know about them, can access them, and can move between different services without difficulty. Patients and carers often described struggling to find information, understand what support was available, or coordinate care between different organisations.



Images AI generated from project data

Conversations with health and care professionals

We have also spoken to 20 **healthcare professionals,** including specialist physiotherapists, nurses, and charity staff. They identified several key priorities for improving care for people with APS. We will keep those suggestions in mind when building a set of recommendations towards establishing a standard care pathway.



Contact Us

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Based on these preliminary findings, we developed an illustration that highlights the challenges encountered by people with APS across their care journey.



Illustration by www.adajusic.com

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Review of published studies

We are conducting a synthesis of the published literature, including 49 articles/policies/guidance written by academics and professionals who looked into services to support people affected by APS. We selected literature that relates to the information gathered during the interviews. This helps us understand which models have been proved useful, what support people currently receive, and what support they may need but are not getting. We also aim to explore the reasons for these gaps in support. The literature showed recurring explanations for why people with APS struggle to access care and the following types of service changes are consistently proposed as solutions:

1. Earlier diagnosis and access to specialist care
2. Multidisciplinary and integrated care
3. Earlier palliative care involvement
4. Advance care planning and communication
5. Support for caregivers
6. Addressing unmet needs and fragmentation.

Community of Practice - please Join!

The community of practice continues to grow in membership. We meet quarterly, meetings run for an hour. These involve updates from the Improve APS study, which have been a springboard for some useful discussions

For more information, please follow this link: ***How to join a forum to share research to improve APS care1.pdf***

Second project workshop in London, October 2026

Stakeholders from across England met in London on the 21st of October to discuss priorities and potential solutions to improve APS care. This included those with lived experience, charity contributors and clinicians, as well as the research team and health economists.



Diversity and Inclusion

We're delighted to have received funding from ARC East of England to help us connect with a wider range of patients and carers.

This support will help us reach people from communities that are often under-represented. We are working to reach and learn from a wider range of people living with these conditions, building links with **under-represented communities (Asian and Afro-Caribbean/Latino)** and ensuring more voices help shape our work.

Please contact us if you have any links that may assist in this.

Conference presentations

Rare Summit 2026

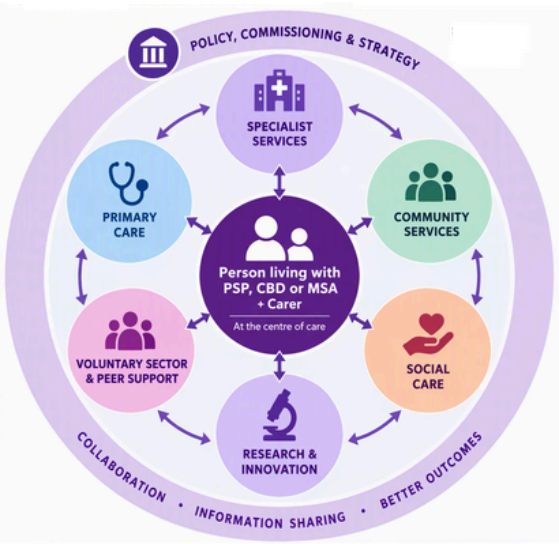
Honey-Anne Greco attended the Rare Summit 2026 conference held by the Cambridge Rare Diseases Network in October 2026. She presented a poster [in the picture] to showcase our work and the initial findings described in the project update. Conferences are also network opportunities, to engage with other study groups.

Neuro26

Annalisa Casarin, Honey-Anne Greco, Janet and Boyd Ghosh attended the PSP/CBD international conference in London in November 2026 and presented a poster about the work of the project and the initial findings and illustrations found in the project update section.

Project Next Steps

- Analysis of 30 cases and 20 professionals' views to build explanations on how services work and why.
- Development of a whole system map based on the collected information.
- Survey to ask people their preference for a new model of care.
- Try out a solution in different context and places.



Thank you to LEAP members!

The Public Participation Involvement and Engagement Group LEAP (Learning from Experience of Atypical Parkinsonism) has been working with the project team, giving much-valued feedback on documentation and visualisations developed by the team.

They meet regularly to give feedback as the project has been developing. They attended the workshop in London on 21st October and contributed their lived experience to the discussions. We have been tracking the contributions from the LEAP group, which so far have been positive, with some areas for the team to continue to develop. One group member commented: "I had no idea really what on earth my role being. You know, gradually, I've come to see that I do have a contribution because it's been so inclusive."

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