

Research questions developed at the HSP Support Group 2025 AGM

Potential research topic areas were identified from previous AGM table discussions and surveys conducted by the UK HSP Support Group's chairman. These were used to develop topic guides to facilitate a 1 hour table discussion at the 2025 AGM. Key points from the table discussion were used to formulate the following research questions. We thank Professor Jonathan Marsden, Dr Lisa Bunn and Gabby Gonzalez-Chan for their help with facilitating the table discussion.

We welcome researchers to help us answer these questions. This could be a master dissertation or developed further for PhD thesis or larger grant applications.

Please let us know (sianging.lee@nhs.net) if you are interested in taking up any of the following research questions so we can coordinate between researchers.

Physical symptoms research questions

Balance

1. What is the impact of biomechanical changes, spasticity, sensory loss, paresis and cognition on balance difficulties in HSP
2. What are the effects of strengthening or multi-sensory balance retraining on balance in HSP?
3. What is the impact of walking aids on balance and walking?
4. What are the long term outcomes with hip and knee joint replacement therapies in HSP compared to people without the condition?
5. What is the clinical and cost effectiveness of different gait aids on mobility and MSK symptoms?

Bladder

1. What bladder symptoms are commonly experienced in different HSP subtypes?
2. How does the effectiveness of pharmacological therapies for bladder symptoms vary depending on the severity and subtype of HSP
3. What is the social and mental health impact of bladder symptoms in HSP?
4. What is the most appropriate objective measure to quantify bladder symptoms in HSP? (to develop one that is HSP specific if one does not exist)

Movement Disorders

1. What is the prevalence of restless legs symptoms and spasms in HSP?
2. What are the effects of medications and management on restless legs symptoms and spasms in HSP?
3. What is the impact of restless legs symptoms and spasms in HSP on sleep quality and fatigue?
4. What is the link between HSP and Parkinson's Disease?

Musculo-skeletal Symptoms

1. What are the site, severity and cause of common Musculo-skeletal (MSK) symptoms in HSP?
2. How are MSK symptoms affected by HSP severity and mobility levels?
3. How are upper limb MSK symptoms affected by alternative walking aids?

Mental health research questions

Communicating HSP diagnosis

1. What is the diagnostic journey for HSP patients?
 - To explore if literature already exist
 - To explore with neurology clinicians if this research would be helpful
 - Are there any lessons learnt
2. How can we optimise the experience when patients first receive their HSP diagnosis?
 - What are HSP patients experience of being told their HSP diagnosis
 - How can this be improved within the constraint of scarce NHS resources?
 - What are the experiences of clinicians when delivering a HSP diagnosis?
3. What support are given to patients newly diagnosed with long-term neurological conditions?

Mental health support

1. What are the contributors and risk factors of poor emotional and mental health wellbeing in HSP patients and carers?
2. How do HSP patients and carers manage their mental health needs?
 - What are the experience, enablers and barriers of HSP patients and their carers accessing mental health support?
3. How can we support HSP patients with acceptance of their diagnosis
 - What are the barriers and facilitators to acceptance
 - Are conventional psychological interventions effective in HSP patients?
4. What psychological interventions, that worked well in other neurological conditions that affects mobility, could be adapted for HSP?
5. To co-develop self-help interventions or supporting materials with HSP patients, carers and professionals

Research project

Here is a research project developed at the table discussion. We would welcome researchers to take on this project.

Research Title

Mutual Support Beyond Care: Enhancing Peer-to-Peer Resilience Between Individuals Living with Rare Diseases and Their Primary Relationship

Research Aim

To explore how mutual, peer-to-peer emotional and practical support between an individual living with a rare disease and their primary relationship (e.g. partner, parent, sibling, or close friend) can be harnessed to foster resilience, wellbeing, and relational strength, potentially surpassing the efficacy of traditional one-to-one mental health interventions.

Research Objectives

1. Investigate the nature of peer-to-peer support within close relationships affected by rare disease.
2. Identify key enablers and barriers to mutual support when one person is living with a rare disease.
3. Examine how relationship roles evolve over time, particularly as informal caregiving emerges.
4. Co-design tools, training, or guidance to equip both individuals in the relationship to support one another more effectively.