

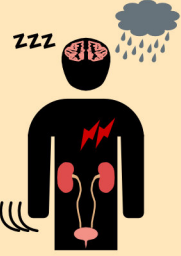
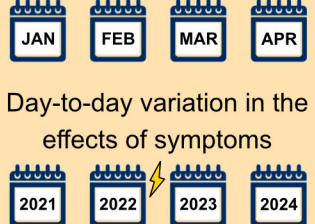




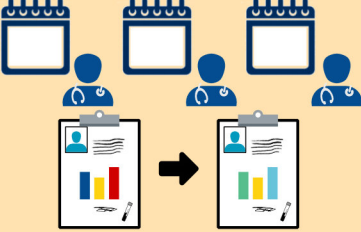


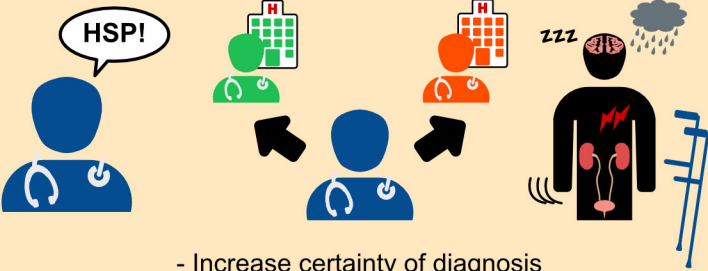
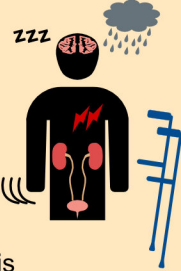
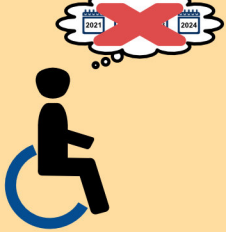
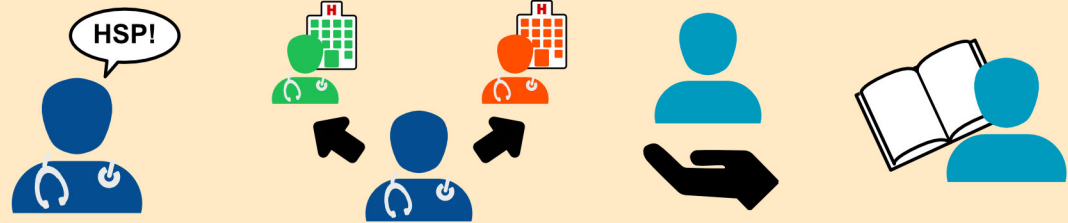




	First symptoms	Diagnosis	Treatment	Monitoring	
Disease	 <p>Childhood      Age 30 - 50</p> <p>Early symptoms are often unspecific</p>	 <p>90+ different disease types. Misdiagnosis is common</p>	 <p>Possible symptoms: fatigue, urinary issues, pain, depression, spasms, cognitive problems</p>	 <p>Day-to-day variation in the effects of symptoms</p> <p>Slow progression of symptoms. New symptoms can develop</p>	 <p>Understand how to accept life with HSP</p>
Clinic	 <p>Early symptoms in people with HSP can include balance issues and tripping</p>	 <p>Clinical diagnosis after excluding other conditions</p>	 <p>Genetic diagnosis might be inconclusive</p>	 <p>Regular follow-up. Personalized plan changes over time with progression</p>	 <p>Plan to consider: future generations; changes at work; modifications at home</p>
Challenges	 <p>Knowledge of HSP is low in many healthcare professionals</p>	 <p>- Increase certainty of diagnosis - Referral of people with HSP to different expert centres - Awareness and prediction of all HSP-aspects</p>	 <p>No cure for HSP, only symptomatic treatment available. Research &amp; clinical trials needed</p>	 <p>Not all people with HSP want to plan. Need for personalized support</p>	
Goals	 <p>- Clinicians should be able diagnose HSP and know experts to refer people with HSP to - Support for people with HSP after diagnosis, including physiotherapy and stretching - Providing people with HSP with information and treatment options</p>	 <p>Get people with HSP to maintain a routine with physical activity. Best quality of life possible.</p>	 <p>Providing information about support networks; current research work; patient registries</p>		