

The Spinocerebellar Ataxia Health Index Study (SCA-HI)

Principal Investigator: Chad Heatwole, MD, MS-CI

What: The researchers are creating a patient-reported measure of health for patients with spinocerebellar ataxia (SCA). This study is being conducted by Dr. Chad Heatwole from the University of Rochester. The study aims to identify the symptoms that have the greatest impact on quality-of-life for individuals with SCA. This will help guide future SCA research. This online study involves completing demographic questions about yourself and a survey on your SCA symptoms.

What's involved: Completion of an online survey, which includes demographic questions and SCA symptom questions. The survey will take approximately 20 minutes to complete, and all responses will be strictly confidential. Your survey will be completely anonymous. You may skip any questions you do not wish to answer.

If you find answering these questions upsetting in any way then please contact the Ataxia UK helpline (0800 995 6037, Mon-Thurs 10:30-14:30, or email help@ataxia.org.uk), or discuss this with your GP or neurologist, or someone in your support network.

Who can participate: Individuals ages 18 years and older with SCA.

How to participate: Interested participants may take the online survey through the following link: <https://redcap.link/SCAsurvey>

Questions? Comments? Any questions or comments can be directed to Preshetha Kanagaiah at 585-210-2563 or email preshetha.kanagaiah@chet.rochester.edu.

Note: If you would prefer to complete the survey on paper or over the phone, please contact Preshetha Kanagaiah at 585-210-2563 email preshetha.kanagaiah@chet.rochester.edu.