

The SMS Springboard Project

Community Progress Dashboard

Project aim

The project aim is to better understand the health and well-being of people with Smith-Magenis Syndrome (SMS), using anonymised NHS healthcare data.

Project partners

The SMS Springboard Project is a research study being carried out at the University of Cambridge (lead researcher Dr Kate D Baker) in partnership with the SMS Foundation. We will also involve other syndrome groups and their support organisations (e.g. PWSA).

Project questions

- **Prevalence** – How many people have a recorded diagnosis of SMS, and how does this vary by age, sex, ethnicity, and location?
- **Health Conditions and Life Expectancy** – What are the most common physical and mental health conditions in people with SMS?
- **Healthcare Use** – How often, and for what reasons, do people with SMS visit their GP or go to hospital?
- **What is specific to SMS and what is shared with other groups** - We will also analyse information about the health and wellbeing of people with Prader-Willi Syndrome (PWS), people with intellectual disabilities (any cause, but not SMS or PWS), and people without intellectual disabilities.

Project timeline

The project started in October 2024, and is expected to last for 3 years. Here is an approximate timeline of how we hope the project will progress. We will update this as things change:

Year	0 (2024)	1 (2025)	2 (2026)	3 (2027)
Project phase	<ul style="list-style-type: none"> Obtaining funding Forming partnerships 	<ul style="list-style-type: none"> Planning the project Obtaining data 	<ul style="list-style-type: none"> Analysing data Understanding results 	<ul style="list-style-type: none"> Communicating results Planning future actions
Community activities	<ul style="list-style-type: none"> Mount Cook weekend 	<ul style="list-style-type: none"> Community webinars 1 Families day 	<ul style="list-style-type: none"> Community webinars 2 Communications working group 	<ul style="list-style-type: none"> Communications working group Community webinar 3
Key milestones	<ul style="list-style-type: none"> Recruit post-doctoral researcher (Millie Wagstaff) 	<ul style="list-style-type: none"> Submit CPRD data access proposal 	<ul style="list-style-type: none"> Obtain preliminary results Share results for community feedback 	<ul style="list-style-type: none"> Present results at conferences Submit journal article Policy event Submit new funding applications
On track?				

Community Webinar 1

- Held online: 25 & 27 March 2025
- The purposes of these sessions were to
 - introduce the study researchers and SMS community members
 - discuss the importance of involving the community throughout the project
 - explain the background and aims of the project
 - gather community feedback and input on the study design
 - plan next steps for maintaining engagement and involvement throughout the project
- The webinars were a powerful reminder of just how much insight families hold, and how essential your lived experience is in shaping meaningful research. We're so grateful for your honesty, ideas, and support.

What We Heard from You

- Ten parents and carers joined in, offering valuable insight, especially about supporting adults with SMS, a life stage that is often overlooked.
- You identified important physical health areas we had missed, including sexual and reproductive health, cancers, movement problems like tremors, and vascular problems such as aneurysms and phlebitis.
- You also identified additional mental health concerns, such as OCD and eating disorders.

What Happens Next

- We're updating our list of health conditions to include the ones you raised within the CPRD proposal if feasible.
- We're working to make sure the study captures not just formal diagnoses, but also important symptom-level information.
- We will let you know when the CPRD proposal is submitted, and any feedback we receive and changes we need to make.
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- You also identified additional mental health concerns, such as OCD and eating disorders.