

June 2025

We're writing to you as June is **Scleroderma Awareness Month**. If you have, or are living with someone who has scleroderma, the leading charity [SRUK](#) has lots of helpful resources. You can also telephone their **helpline** on 0800 311 2756, 365 days a year, 9am to 7pm.

Update from the RECORDER team:

We had an insightful meeting of the RECORDER Public Partnership on Tuesday 10th June. We are ever so grateful for all those who joined us, especially for the first time. We had two fantastic discussions about project ideas looking at earlier diagnosis and experiences of stopping taking steroids. Things we learned are shaping funding applications we are writing to enable our research to progress in these areas.

Upcoming opportunity for involvement:

Since the meeting, one of our patient partners has made us aware of the RAISE study looking at what NHS support is needed by people with rare rheumatic conditions. If you'd like to know more and input into the survey, please click [here](#). If you're an X (formerly Twitter) user, you can also follow the study's progress with @CHCR_UWE.

Kind regards,

Stephanie and the RECORDER team



Registration of Complex Rare Diseases - Exemplars in Rheumatology

School of Medicine

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