

REIS: A Citizen Science journey for and with people with rheumatic conditions

Kirsten van Mierle¹, Eline te Braake³, Rita Schriemer¹,
 Clementine Ophuis, Valérie Bodelier (on behalf of the group of patient representatives)
 Christiane Grünloh³, Ria Wolkorte²

REIS stands for *Reuma en Ik – Self-management* and is a project to investigate self-management strategies that people with a rheumatic condition apply. Our aim is to provide an overview to inspire others, inform healthcare professionals, and explore opportunities for research. This project is completely set up and carried out together with people diagnosed with a rheumatic condition.

Citizen Science

Patient Representatives

- Share collective experiences of self-management
- **Re-use** what is know and **reduce** burden
- Personal versus universal: we want to use our own words & explain the WHY
- Having our voices heard and our expertise mirrored in the survey
- Distinguish between the WHAT and WHY they apply a self-management strategy
- We want to share with and learn from others: We need a tool for that.

Researchers

- Ensuring relevance and learn about self-management
- Making data available in a repository
- Correct assumption to use universal categories for minimum burden → qualitative survey
- Exceeded expectations (N=254, number of strategies = 1170)
- Adapting analysis framework to reflect both WHAT and WHY
- Highlighting experiential knowledge in academia. Identifying the need for co-designing a tool.

