

The Scleroderma Patient-centered Intervention Network (SPIN): Engaging Patients in Rheumatology Research



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Background

- Patient engagement in research and care is linked to improved health outcomes, increased uptake of care, and reduced healthcare costs. It is increasingly seen as a core component of high-quality patient care.
- Founded in partnership with patient organizations, the Scleroderma Patient-centered Intervention Network (SPIN) is a collaboration of patients, caregivers, healthcare providers, and researchers who work together to develop and test interventions to improve quality of life in people with scleroderma.
- From its inception, SPIN has sought to maximize the impact of its research by engaging patients to take an active, meaningful role in research.

Objective

To describe steps SPIN has taken to engage patients and subsequent results.

Methods

SPIN has engaged a diverse, international group of patients to serve on all levels of SPIN's organization.

Table 1: Overview of various patient roles in SPIN's organization.

SPIN Committee/Team	# Patient Members	Role
Steering Committee	3	Oversee SPIN's research direction and advise on cohort recruitment/retention, intervention prioritization and development, feasibility and full-scale trials of interventions, publications, finances, and administrative issues.
Patient Advisory Board	8	Advise the Steering Committee's activities so that SPIN projects maximally reflect the needs of scleroderma patients; promote successful knowledge transfer within the scleroderma and rare disease communities.
SPIN-SSLED Advisory Team	10	Work with health experts and researchers to develop, test, and disseminate the SPIN Scleroderma Support group Leader Education (SPIN-SSLED) Program.
SPIN-PACE Advisory Team	10	Work with health experts and researchers to develop, test, and disseminate the SPIN Physical Activity Enhancement (SPIN-PACE) Program.
Intervention Project Teams	1 per team	Co-lead the development and design of SPIN's various online interventions to support people with scleroderma.

These and other patients participate in all phases of SPIN's research, from (I) *Preparation*: generating research questions and priorities, to (II) *Execution*: designing interventions and trial methods, and (III) *Translation*: disseminating interventions and study results.

Results

Table 2: Summary of patient involvement in each phase of SPIN's research.

(I) Preparation Generating research questions and priorities	SPIN has determined patient research priorities through numerous outreach initiatives, including: <ul style="list-style-type: none">• Administering an online survey soliciting suggestions for future research projects, completed by 124 patients• Conducting over 20 focus groups with patients and caregivers• Collecting data about common problems in scleroderma and support needs from SPIN's ongoing cohort of over 1,800 scleroderma patients The Patient Advisory Board uses these data to select and prioritize topics for interventions.
(II) Execution Designing interventions and trial methods	Patients contribute to research execution by: <ul style="list-style-type: none">• Co-leading Project Teams that develop SPIN interventions• Reviewing all intervention content• Helping select and validate outcomes for SPIN's clinical trials• Providing other feedback on study designs and procedures
(III) Translation Disseminating interventions and study results	<ul style="list-style-type: none">• The dissemination of online interventions will be led by SPIN's partner patient organizations, who will advertise and distribute the interventions free-of-charge through their websites• Reflecting their engagement, patient members of SPIN have co-authored 25 peer-reviewed articles, 6 oral conference presentations, and 51 conference poster presentations

Image 1: Patient members of SPIN's Patient Advisory Board. Left to right: Karen Gottesman, Catherine Fortuné, Joep Welling, Maureen Sauvé, Karen Nielsen, Geneviève Guillot, Dominique Godard, and Alexandra Portales.



Conclusions

Patients actively participate at all levels of SPIN's organization, contributing significantly and sometimes leading phases of SPIN's research projects. SPIN's patient engagement process can serve as a model for research initiatives in other rheumatic and rare diseases.



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