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

Objectives: 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-centered 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. The objective of this presentation is to describe steps SPIN has taken to engage patients and subsequent results.

Methods: A diverse, international group of patients serve on all levels of SPIN's organization, including: 3 patients on SPIN's Steering Committee; 8 patient members on the SPIN Patient Advisory Board; 9 patient members on the SPIN-Scleroderma Support Group Leader Education (SPIN-SSLED) Program Team; and one patient Co-Leader of each Project Team for SPIN's online interventions. SPIN engages these and other patients in all phases of research, from (I) Preparation: generating research questions and priorities, to (II) Execution: designing interventions and trial methods, and (III) Translation: disseminating SPIN's online programs and study results.

Results:

(I)Preparation: SPIN has determined patient research priorities through numerous outreach initiatives, including administering an online survey soliciting suggestions for future research projects, completed by 124 patients; conducting over 20 focus groups with patients and caregivers; and collecting data about common problems from SPIN's ongoing cohort of over 1,700 scleroderma patients. The Patient Advisory Board uses these data to select and prioritize topics for interventions.

(II) Execution: Patients contribute to research execution by: co-leading Project Teams that develop SPIN interventions; reviewing all intervention content; helping select and validate outcomes for SPIN's clinical trials; and providing other feedback on study designs and procedures.

(III) Translation: 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.

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