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Patient information and education

POS1497-PARE POST-TRIAL SURVEY OF PARTICIPANTS OF A PHASE 3 CLINICAL TRIAL IN SSC-ILD

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Background: The SENSISC® trial (2015–18) was a large clinical trial (n=576) investigating the efficacy and safety of nintedanib in patients with systemic sclerosis-associated interstitial lung disease.1 The clinical research sponsors (CRS) collaborated with the scleroderma patient community advisory board (CAB) regarding the design, implementation and conduct of the trial.2 As part of this collaboration, the CRS and CAB developed a post-trial survey for SENSISC® participants. The use of the developed patient-centric materials was optional for the sites.

Objectives: The objectives of the SENSISC® post-trial survey were to gain experience in collecting real-world information and trial satisfaction data from patients to inform and improve future patient centric clinical research.

Methods: SENSISC® trial participants who were involved in the extension trial SENSISC®-ON completed a post-trial survey covering nine multiple-choice questions about three main topics:

- [1] Recruitment – Where do patients usually search for clinical trials and how did they become aware of SENSISC®?
- [2] Motivation & Retention – What motivated patients to start and continue participation in SENSISC®?
- [3] Challenges & Wishes – What were the challenges during trial participation and how can future clinical trials be improved regarding patient centricity?

Results: A total of 125 participants completed all survey questions. Participants could select more than one option. A total of 51 patients reported that they are usually not actively looking for trials. For those actively searching, the most common sources to learn about trials were specialists/general practitioners (GPs) (46 patients) and internet search engines (20 patients), followed by patient organisations (12 patients). Of note, 78 patients would pay attention to printed materials, such as a card/flyer/poster in a doctor's office and get in touch with a trial/study site. Back in 2015–2017, during recruitment for the SENSISC® trial, the majority of the patients who answered the survey were made aware via their specialist/GP (116 patients), whereas 5 were made aware via patient organisations and 4 via the internet.

The most frequent motivations to join the trial were 'hope to receive an improved therapy' (98 patients), to help other patients (64 patients), and on the recommendation of their specialist/GP (81 patients). Similarly, the most liked aspects of the trial were the 'opportunity to receive an improved therapy' (92 patients) and 'to support the development of an improved therapy for my illness' (90 patients). More than half of patients reported 'continuous observation of general health' (72 patients) and 'advice from GPs/specialists' (71 patients) as motivation to stay in the trial (Figure 1).

'Concerns about side effects' (72 patients) and 'not knowing whether the trial medication will work for me' (63 patients) were reported as the least liked aspects of the trial. Travel to the site was reported as a challenge by 21 patients.

To improve clinical trials, patients requested more patient-friendly information (50 patients) and multiple formats of information material (46 patients). Finally, 48 patients expressed the desire to communicate with other trial participants.

Conclusion: The SENSISC® post-trial survey is a unique approach to receive real-world feedback from trial participants, and these pilot data will help improve future clinical trials and communication. The results highlight the importance of reaching patients who may not be actively looking for clinical trials.

Figure 1. Motivation to stay in the SENSISC® trial^{1,2}

¹More than one option could be selected.

²Data collected on 9th January 2021

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Building patient led organisations

POS1498-PARE LAUNCHING A NEW RELAPSING POLYCHONDRIITIS ("RP") PROGRAM

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Background: In 2011, I was diagnosed with relapsing polychondritis ("RP"), a debilitating and sometimes fatal rheumatic disease that is characterized by inflammation of cartilage and other tissues. The disease affects multiple organs, particularly cartilaginous structures such as the ears, nose, airways, and joints as well as eyes, skin, heart valves and brain. The cause of RP remains unknown and there currently is no cure for the disease.

As a patient, I had the opportunity to be evaluated by an incredible team of multidisciplinary expert medical professionals. While interacting with these experts, it was evident that there were tremendous unmet needs in the areas of diagnosis and treatments. As a retired Registered Nurse, it was clear that targeted research initiatives would be required to combat RP.

Objectives: After diagnosis, I realized that I could focus on my specific case or combat RP more broadly and help others. I decided to live my life with the purpose of helping others.

Methods: While fighting RP, I met many highly skilled, collaborative research scientists, especially at annual gatherings of rheumatology professionals. In 2017 in San Diego, I participated in an RP study group that received a tremendous response from participating clinicians, clinical and basic scientist researchers, patients, and patient advocacy groups.