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SScEntry: a personal disease diary app for Systemic Sclerosis patients

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Background:

Systemic Sclerosis (SSc) is a connective tissue disease characterized by severe alterations in the microvasculature and progressive fibrosis of the skin and internal organs [1]. Management of SSc is not easy, for both patients and physicians [2]. Symptoms are manifold and have a significant impact on patient's daily autonomy and psychological well-being.

Objectives:

SScEntry (SSc data Entry tool; Figure 1) is a solution conceived to assist SSc patients in monitoring their disease, as a kind of "sentry". The core idea is to provide patients with a personal diary to annotate and track the onset, evolution and resolution of symptoms as well as any changes in their general health condition, through an app for iOS and Android smartphones and tablets.

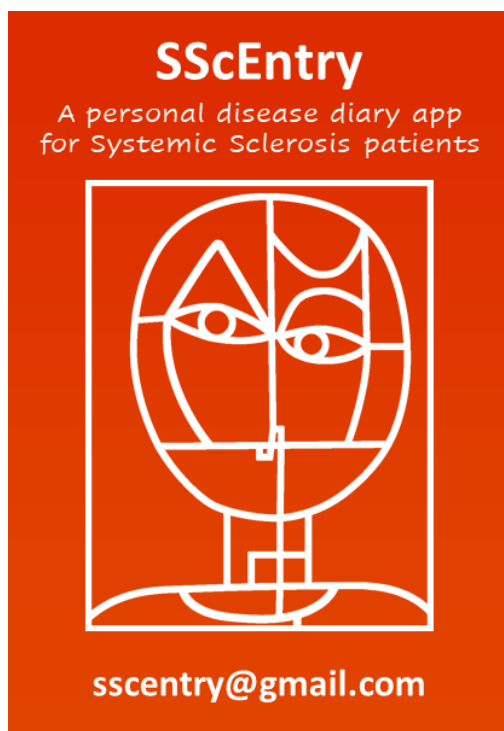


Figure 1. SScEntry logo.

Methods:

SScEntry is a smartphone/tablet app designed by rheumatology and computer science engineering specialists in close partnership [3]. A carefully designed user interface (UI), inspired to a social network wall, allows annotating the evolution of symptoms by means of standard clinical investigation methods such as scientifically validated questionnaires. The UI facilitates data collection through speech-based interaction as well as touch and gestures optimized for patients with finger skin lesions and joints impairments. User engagement over the course of time is fostered by: follow-up reminders to update information on the evolution of past events and periodic questionnaires for general health assessment; the integration of symptom photos taken with on-device camera and health data collected from wearable devices; gamification features. Privacy and security have been a primary design concern, with app access protection and full on-device data encryption; no personal data transmission occurs without explicit user consent. SScEntry generates a disease activity summary report, for displaying to the physician during visit or emailing/printing.

Results:

SScEntry is ready for Android and iOS smartphones and tablets. All planned features have been implemented (Figure 2). Currently supported languages are English and Italian. Areas of interest include vascular, cutaneous, articular, visceral (gastro-intestinal and cardio-pulmonary) as well as relationship, sexual and working life.



Figure 2. SScEntry features.

Conclusion:

Novel Narrative-based Medicine approaches are getting increasing attention to enhance the mutual understanding between patient and physician, reinforcing the therapeutic adherence

at the core of healthcare. This is particularly important with chronic and disabling diseases like SSc. Involving patients in disease management with SScEntry will increase their compliance and confidence, with benefits on psychological well-being. Expected benefits for rheumatologists include better evaluation of target therapy and outcomes, as no data on disease activity is lost during the patient clinical history.

References:

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