SESAME Quiz: a playful online questionnaire to assess patients’ knowledge about Sjogren’s syndrome

What was done?
A playful online questionnaire was designed and implemented to assess patients’ knowledge about Sjogren’s syndrome.

Why was it done?
It is a rare, systemic and unknown autoimmune disease with damage to exocrine glands. This complex disease is often difficult to understand for patients. We needed to assess the impact of our patient education program on Sjogren’s syndrome (SESAME) in order to improve it continuously.

How was it done?
- Interprofessional team (3 pharmacists, 3 rheumatologists) with skills in patient education
- A 4 patient-group participating in the education program
- Definition of a competency framework for patients with Sjogren’s syndrome
- Identification of quality requirements for a questionnaire
- Scoring system
- Proposition of answers
- Face validity (interprofessional team and patients)
- Feasibility (patients)
- Reproducibility (patients contacted to complete the questionnaire twice, intraclass correlation coefficient = ICC calculation)

What has been achieved?
https://etp-rhumato.typeform.com/to/qsVhR1

Flash this code to access the online demo of the questionnaire that you can fill in

28 questions
50 points
4 categories

Face validity
- Interprofessional team validation
- Considered as « very good » by 15 patients out of 18
- Understandable language
- Unambiguous sentences
- Types of questions
- Utility of every questions
- Relevance of the illustrations
- Except the item « difficulty » considered as « very good » by 13 patients out of 18

Feasibility
- Average response time = 19 minutes
- Considered as « very good » by 15 patients out of 18
- Length of the questionnaire
- Functionality (before patient education then one month later)
- Web access

Reproducibility
- 1st answer
- 2nd answer
- 25 patients
- n=24
- n=1
- Age: 54 years min-max[23;74]
- 4 years min-max[1;20] since the diagnosis of SGS
- ICC 0,87 IC95%[0,74-0,94]

n = 2 x 25 responses on smartphone, tablet or computer

30,5 out of 50 points min-max[24,5;44]
With patient education beforehand
41,5 out of 50 points min-max[33,5;44]
With patient education beforehand
Significant difference (p = 0,007)

What is next?
The SESAME quiz is now available for free and all the Hospital Centers can use it for Sjogren patients follow-up, by contacting crmr.sjogren@aphp.fr (Rheumatology department, Hôpital Bicêtre, France).