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## 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)

Criteria	Patients' contribution	Examples of solutions
Opportunity to interact	X	First-person questions
Means of expression	X	Multiple-choice questions, open-ended questions
Scientific quality		Valid content
Logical sequencing		Links between questions, categories
Easy to understand	X	Clear vocabulary, without phrases, one skill per question
Utility	X	No repetition, objective explanation, proposition of answers
Shortness		Concise questions (< 20 words), one by one on the screen
Bias prevention		Randomized order of answer choices, credibility, no answer in another question
Playfulness	X	Focus on the artwork
Diversity		Different types of questions (true/false, multiple choices, images), on knowledge but also on patient experience
Sharing		Online

## 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

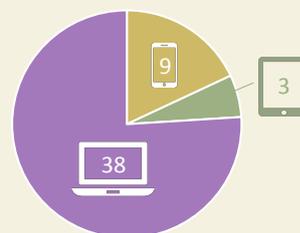
### Feasibility

- ✓ 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

- 1<sup>st</sup> answer
- 2<sup>d</sup> answer
- 25 patients
- n=24 (female)
- n=1 (male)
- 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



- ★ n = 16
- 30,5 out of 50 points min-max[24,5;44] Without patient education beforehand
- + n = 9
- 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 [crm.r.sjogren@aphp.fr](mailto:crm.r.sjogren@aphp.fr) (Rheumatology department, Hôpital Bicêtre, France).