

DEVELOPING A PATIENT SATISFACTION QUESTIONNAIRE

ERN-SKIN ePAG

2019-2020

Activity	Developing a Patient Satisfaction Questionnaire
Area	<i>Healthcare, Communication and dissemination</i>
Duration	6 months
Contact	Marie-Claude Boiteux

1. SUMMARY

i The ERN-Skin¹ gathers together 56 Reference Centres located in 18 European countries. As part of the ERN monitoring system, the ERN-Skin network designed a patient satisfaction questionnaire to measure the impact of the ERN-Skin healthcare provided centers on patients with the aim to improve the quality of care and the performance of these centers.

The patients themselves are best placed to evaluate the quality of care of the centers. For this reason, the ERN-Skin ePAG advocates were asked by the ERN-Skin Coordinator to be part of the design of this questionnaire.

A first draft was prepared by one of the ERN-Skin ePAG advocates but it was way too long and not easy to fill in. So the ePAG advocates decided to work together for 6 months to reformulate almost all the questions and the format of this questionnaire. The final result is a one side A4 sheet, easy to understand and to complete, easy to use and to transform in statistics questionnaire. Reviewed by an English born ePAG advocate and translated by the ePAGs in their mother languages (French, Dutch, German and Danish), this questionnaire covers all patients' needs in terms of satisfaction when they consult a medical doctor in one the ERN-Skin center. This activity is a result of a proven collaboration patients-clinicians and showcases how ePAG advocates can bring added value to the ERNs.

¹ <https://ern-skin.eu/about-the-ern-skin/>

2. INITIAL SITUATION

i The ERNs need to demonstrate that the networks are delivering services and functioning. The ERN Coordinators Working group on Monitoring worked intensively from June 2017 to March 2018 in the preparation of a proposal for ERN indicators.

A set of 18 indicators² were chosen in 2019 to capture the added value following the establishment of the ERNs compared to what exists. These defined indicators should reflect the level of functional collaboration between European healthcare providers and coverage of involved countries in Europe; **level of patient empowerment, contribution and satisfaction** as well as level of knowledge generation through research activities. The ultimate goal being to improve care and treatment for people living with rare diseases or complex conditions.

Therefore, **the process for the measurement of patient satisfaction was defined as an integrated process of monitoring the ERNs.**

In this context, **the ERN-Skin Coordinator asked the ePAG advocates who sit in the ERN-Skin Executive Committee to prepare a questionnaire to measure the level of patient satisfaction after a consultation in an ERN-Skin center.** A first draft was prepared and was shared within the Executive Committee in October 2019. In this back and forth revision, it was commonly decided to considerably change and reduce the content and to modify the format. The current version was way too long (4 pages and 28 questions), was not easy to fill in and was too “country specific” when addressing patients’ needs.

3. CONTRIBUTION TO PATIENT ENGAGEMENT AND/OR IMPROVEMENT OF CARE

i Starting from this first version of the questionnaire, the Skin ePAG advocates decided to work together (online) to revise it and reformulate the questions in order to bring the patients’ views and to get a real European vision of patients’ needs.

To ease the collaboration and the communication among the group, **one ePAG advocate was appointed as the main contact point** between the ePAG group and the ERN Coordination team and was in charge of coordinating the task and gathering all the feedback.

The content was considerably reduced but the most relevant aspects were maintained to make sure that the patients’ satisfaction was captured.

After 2 months of collaborative work, a first version was sent back to the ERN Coordinator and to some sub-thematic groups coordinators to get their feedback. **The goal was to write in language familiar to the target respondents, the patients and their families.** It was challenging to find a common terminology that represents all the needs of patients, the different ERN-Skin disorders as well as the different treatments available across Europe.

Based on this first approach, the ePAG advocates started another round of 2-month. They integrated the clinicians’ suggestions and they reduced the text once more to **one A4 page with 26 short and simple close ended questions. The format of the questions was crucial.** It was decided to include close ended items in order to provide respondents a limited number of response options and to facilitate the analysis. The ePAG advocates added a multiple-choice scale to indicate the level of agreement and to allow a total score of satisfaction.

² https://ec.europa.eu/health/sites/health/files/ern/docs/continuous_monitoring_en.pdf

The clinicians gave their approval on this final version and the questionnaire was disseminated in April 2020 among the ERN-Skin sub-thematic groups.

The questionnaire is divided in 4 main sections (see Annex I below):

- 1/ General information on the patient
- 2/ Consultation and follow-up (19 questions)
- 3/ Treatment prescription and therapeutic research (5 questions)
- 4/ Global satisfaction (2 questions).

A short blank section is available at the end of the questionnaire to add any comments.

Last but not least, **the questionnaire was translated in different EU languages** to be understood by a large number of European patients. Firstly, it was reviewed by an English born ePAG advocate and then it was translated by some of the ePAG advocates in their mother languages (currently it is available in French, Dutch, German and Danish).

This questionnaire as the potential to improve patients care. Its main purpose is to measure the impact of the ERN-Skin healthcare provided centers on patients with the aim to improve the quality of care and consequently the performance of these centers. The ERN coordinator will use this instrument to internally manage the performance of their ERN and identify areas for improvement by taking into consideration patient's experience and needs. The results of this questionnaire will be crucial for the evaluation process of the ERN centers that take place every 5 years.

Another important aspect is the way this questionnaire was elaborated. **The ePAG advocates were involved from the very beginning as they were asked by the Coordinator to elaborate the first draft from scratch.** Their feedback was considered and accepted by the clinicians in all the revision phases. The ePAGs also took into consideration the clinicians' opinions and suggestions to improve the content. In this sense, it was a **fruitful patients-clinicians collaborative work.**

The ePAG advocates brought their views and represented the needs of their wider patient community in all the process.

Ultimately, setting up the questionnaire was an opportunity to **showcase how the ePAG advocates can actively contribute to the ERNs, what is their added value, and what are the SKIN patients' needs in terms of experience and satisfaction in the ERN-Skin centers.**

4. SUCCESS FACTORS

i An **existing and good relationship between the ERN-Skin ePAG advocates and the ERN-Skin Coordination Team** was essential and helped considerably to move the activity forward:

- The SKIN ePAG advocates had a proven good collaboration with the ERN Coordination team.
- Both the ePAG advocates and the clinicians were willing to share ideas for the benefit of the patients. They were open minded to consider the needs of each disease and were able to collect the common needs so that the questionnaire can be usable by all ERN-Skin centers whatever the disease represented.
- Both the ePAG advocates and the clinicians agreed on the need of a questionnaire that meets patients' needs in terms of satisfaction.

- The feedback provided by the ePAGs were taken into account in every revisions of the questionnaire.

A **good communication, coordination and commitment between the ePAG advocates** were also part of the success:

- One of the ePAG advocates was responsible for leading the task, gathering patients' feedback and reporting back to the ERN Coordinator.
- All the current ERN-Skin ePAG advocates were actively involved in this activity and provided relevant feedback.
- The background of the ePAGs was also helpful: one ePAG English mother tongue, another one had special skills on "building a questionnaire" and another one attended the Eurordis Leadership school and brought some innovative approach and ideas.

5. LESSONS LEARNED

i This activity helped to bring the ePAGs together to reach one goal for the benefit of all the patients involved in the ERN and the wider patient community.

The following aspects are considered as lessons learned:

- Having a common goal and a common perspective.
- Only patients' view can really represent patients' needs.
- Designating a leader/coordinator.
- Working closer together to find common words despite the different disorders, countries and backgrounds represented.
- Showing the clinicians a qualitative work and our expertise with trust and mutual respect helps to build a good relationship with them.
- Being involved in this type of activity takes time and need to follow a step-wise approach.
- Facing the difficulty to find the right translation in each language to ensure that the questions reflect exactly what is asked and are understood in each country, for each disorder despite the differences in culture, language, treatments, etc. (lack of resources).
- Finding common needs for the patients.

Next steps:

- The questionnaire has been sent to all ERN-Skin sub-thematic groups with the aim to include maybe additional disease specific questions.
- It will be translated into the missing languages to cover all European countries.
- It will be sent to all the 56 healthcare centers, published on the ERN-Skin website and shared with the patients after each consultation to start collecting the results.

- The ePAG advocates will probably review the content of the questionnaire in the next 2-3 years.
- The ePAG advocates will discuss with the clinicians on a validation process of the questionnaire. **More information on the validation process by Jessie Dubief from EURORDIS can be found [here](#).**

Note: A validated questionnaire refers to a questionnaire that has been developed to be administered among the intended respondents. The validation processes should have been completed using a representative sample, demonstrating adequate reliability and validity³.

3

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5463570/#:~:text=A%20validated%20questionnaire%20refers%20to,demonstrating%20adequate%20reliability%20and%20validity>.

ANNEX I

Patient Satisfaction Questionnaire

ERN-Skin

Satisfaction questionnaire patient consultation

Dear Sir/Madam,

You recently had a consultation in an ERN-Skin Reference Centre. The ERN-Skin gathers together 56 Reference Centres located in 18 European countries. (<https://ern-skin.eu/about-the-ern-skin/>). They aim to improve diagnosis, medical care, social care and information for all patients with the same disease you have, in all Centres, in all European countries.

The purpose of this questionnaire is to improve the quality of care in each Centre of the ERN network and to avoid inequalities of care and patient follow - up at the European level. It is strictly anonymous.

Thank you very much.

1-General Information

Who was the consultation for? Yourself Your Child Someone (child or adult) you are caring for

Which Centre was your consultation carried out in?

Hospital:

Service:

Town:

Country:

What was the reason for consulting the Centre? 1st appointment Follow-up other, please specify.....

Who referred you to this service?

Family doctor

Local dermatologist

Hospital dermatologist (or other medical service) Someone else, please specify:

2-Consultation and Follow-up

N.A. = Not Applicable

	0	1	2	3	N.A.							
Was it easy to find the contact information for the Centre and/or make an appointment?												
Was the consultation adequate from an emotional/psychological point of view?												
Were the location and space of consultation adapted to your specific needs and/or disability (dressing, solar filter, water points, etc.)?												
Was it a multidisciplinary consultation (seeing different specialists during the same consultation or the same day)?												
Did the consultation clearly propose psychological support?												
Did you feel the consultation considered all the necessary specialists to address your care?												
Did you understand the explanations and consequences of the rare disease?												
Do you feel well informed about the disease?												
In the case of a genetic disease, were you adequately informed regarding the inheritance risks?												
In the case of a genetic disease, were you referred to a specific genetics consultation?												
Are you satisfied with the follow-up within the Centre?												
Are you satisfied with the information on how to contact the Centre in case of emergency?												
Did you receive any information about the availability of peer support, such as disease specific national patient organisation and/or an international network and/or a national rare disease alliance?												
Has the Centre set up a local network for your follow-up?												
	0/No			3/Yes	N.A.							
In the case of a local network, it includes psychological follow-up												
In the case of a local network, it includes your local doctor												
In the case of a local network, it includes a nurse												
In the case of a local network, it includes social workers												
In the case of a local network, it includes other members (Please specify.....)												
3-Treatment prescription and Therapeutic research Scale from 0 to 3, 0=no, not at all ; 1=just a little ; 2=yes, but incompletely ; 3= yes and completely ; N.A. = Not Applicable	0	1	2	3	N.A.							
If a treatment already exists for the disease you consulted for, was the aim of the prescribed treatment discussed?												
Were alternative treatments discussed?												
Were side-effects/intensity/risks of treatment discussed?												
Were you given a specific contact in case of problems regarding at-home treatment?												
Do you know if therapeutic research protocols exist for the disease, or its symptomatic manifestations, in the centre where you consulted?												
4-Global satisfaction Scale from 0 to 10, 0=no, not at all ; 10= yes and totally ; N.A. = Not Applicable	0	1	2	3	4	5	6	7	8	9	10	N.A.
Are you satisfied with how the multidisciplinary team took care of you?												
Are you satisfied with the hospital where the centre is located (premises, signage, reception, lift, etc.)?												

Please add any other comments you may feel useful or necessary:

Thank you!

Max Score of satisfaction: 92