Developing a Patient Satisfaction Questionnaire

ePAG Exchange of Good practice

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Marie-Claude Boiteux

ePAG advocate: ERN Skin

European Reference Networks

SKIN

European Patient Advocacy Group

SUMMARY

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1. Background

- ERN-Skin: 56 Reference Centres in 18 European countries

- ERN-Skin ePAG advocates structure: 12 people covering 10 different diseases in these countries: Austria, Belgium, Denmark, France, Italy, Netherlands, UK and Northern Ireland,

- **Patient satisfaction questionnaire**: measure impact of ERN-Skin centers to improve quality of care and performance

- ePAG advocates main contributors to development of questionnaire

2. Initial Situation

- ERN Coordinators Working group on Continuous Reporting of ERNs: 18 ERN indicators to capture added value:
  - Level of **patient empowerment, contribution and satisfaction** & level of knowledge generation through research activities ➡ process for measurement of satisfaction defined as integrated process of ERN monitoring

- ERN-Skin Coordinator asked ePAG advocates in ERN-Skin Executive Committee to prepare a questionnaire to measure level of patient satisfaction after consultation in an ERN-Skin center

3. The questionnaire (see Annex 1)

The questionnaire has 26 items and it is divided in 4 main sections:

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.

- It covers all patients’ needs in terms of satisfaction and was developed by ePAG advocates in English and then translated in their mother tongues (French, Dutch, German and Danish)

- It has the potential to improve patients care by measuring impact of ERN-Skin centers on patients to improve the quality of care

- ERN coordinators will use this instrument to internally manage the performance of their ERN members and identify areas for improvement by taking into consideration patient’s experience and needs

- Results will be crucial for the evaluation process of the ERN centers that take place every 5 years

- **Challenge: find a common terminology representing all needs of patients, different ERN-Skin disorders & treatments available across Europe**

4. Contribution to patient engagement

- **8 ePAG advocates covering 8 different disorders were involved from the very beginning** as they were asked by the Coordinator to elaborate the draft.

- **Fruitful patients-clinicians collaborative work:** ePAG advocates brought their views and represented the needs of the patients in all the process. Their feedback was considered and accepted by the clinicians in all the revision phases.

- The questionnaire **showcases 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.

- The questionnaire is a good practice of patients-clinicians collaboration

5. Success Factors

- **Good collaboration between ePAG advocates & clinicians/ERN Management Team** i.e. willingness to share ideas for the benefit of the patients, open minded to consider the needs of each disease represented

- ePAG advocates & clinicians agreed on the need of a questionnaire that meets patients' needs in terms of satisfaction

- Feedback provided by the ePAGs were taken into account in every revisions of the questionnaire

- **Good communication, coordination and commitment between the ePAG advocates**
  - Almost all the ERN-Skin ePAG advocates were involved in this activity and provided relevant feedback at different points in time
  - ePAGs Background : English mother tongue, special skills on "building a questionnaire", leadership and innovative skills (Eurordis Leadership School)

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6. Lessons Learned

- Only patients' view can really represent patients' needs
- Finding common needs for the patients
- Having a common goal and a common perspective
- Designating a leader/coordinator
- Working closer together to find common words despite the different disorders, countries and backgrounds
- 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
- Showing the clinicians a qualitative work and the ePAG expertise with trust and mutual respect helps to build a good relationship with them

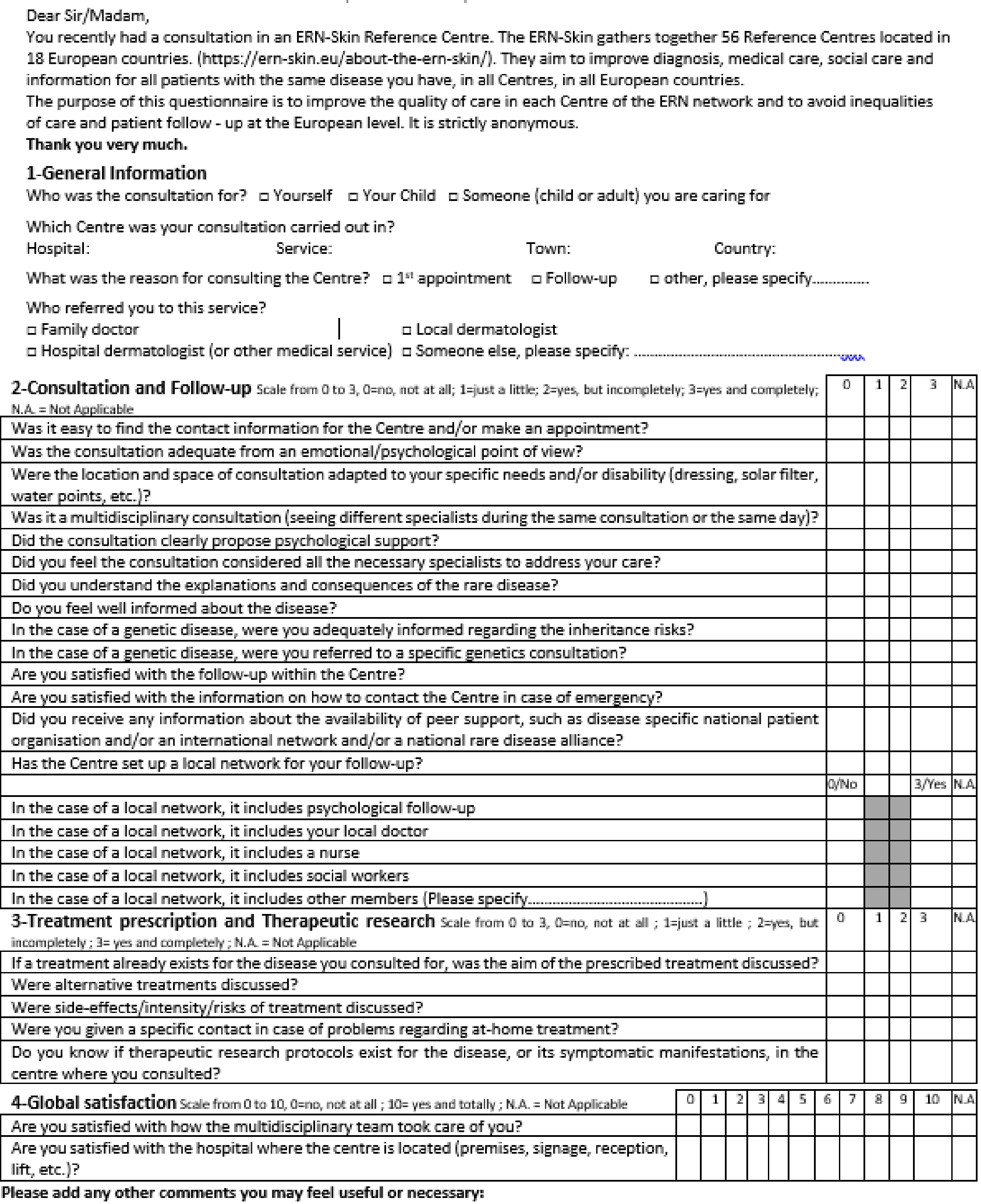
7. Next steps

- Add 1 or 2 questions related to specific ERN-Skin disorders
- Translate it in other languages (only English, French, Dutch, German and Danish as of today) to cover all European countries and ERN-Skin centers
- Publication on the ERN-Skin website
- Share the questionnaire with the patients after each consultation to start collecting the results
- Revision of the content of the questionnaire in the next 2-3 years
- Discussion with the clinicians on a validation process of the questionnaire

Thank you!

Annex 1

Patient Satisfaction questionnaire



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 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
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:

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