



THE H-CARE PILOT SURVEY

ePAG Good Practices

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EURORDIS.ORG

Monitoring patient experience in ERNs

Patient experience and satisfaction is part of the **18 core indicators for the continuous monitoring of ERNs**, but has not been defined yet.

The development of a **Common Feedback Mechanism** that would regularly gather patient experience and satisfaction on the care received across the 8000+ rare and complex diseases, across the 24 ERNs and across Member States would allow to:

- Measure the **evolution of care experience** over time and across Europe;
- Provide information in order to align **strategic decisions and operational delivery of the ERNs** with patients' needs and experiences, specifically the development of healthcare pathways and treatment protocols;
- **Avoid duplication of efforts** through pooling of resources (human, financial, tools such as software, etc.) which will result in economies of scale;
- **Ensure robust, comparable and independent validated data and results** by using the same survey methodology across ERNs;
- **Achieve sufficient survey sample size and coverage** of the ERNs patient population.

Objectives of the H-CARE Pilot Survey

The H-CARE Pilot Survey has been initiated by **4 ERNs (eUROGEN, ErkNet, LUNG and Genturis)** and supported by Rare Barometer, the survey initiative of EURORDIS-Rare Diseases Europe. Its aim is to test the implementation of a patient experience survey on a **small scale** to ensure:

- **Sustainability of the feedback mechanism:**
 - Understand how to best operationalise **across ERNs and Member States**, and explore the **limits and challenges** of administering the survey, response rate, analysis, robustness of the results, etc.
 - Provide insights into how to **implement this on a large scale** in terms of **resources, time and budget**.
- **Robustness of the survey:**
 - Agree on the **dimensions** to measure and the **best tool / questionnaire** to measure patient satisfaction.
 - Define the best means to get **a sufficient number of respondents** by breakthroughs (ERNs, languages...).

Methodology

1. Creation of a **Topic Expert Committee** with ERN coordinators and clinicians, ERN managers and ePAG representatives from eUROGEN, ErkNet, Genturis and LUNG.
2. Definition of **dimensions** for the survey: follow-up, information on social services and benefits, humanistic aspects, information on treatment, information on therapeutic education, information on diagnosis / prognosis, general aspects of care delivery.
3. **Literature review** to find validated scales with dimensions defined above, for rare and complex diseases patients and caregivers > no validated scale meets all requirements.
4. **Choice of an existing scale**: the Topic Expert Committee chose the PACIC-S (Patient Assessment of Care for Chronic Conditions Short-Form).
5. **Adaptation of the wording of the scale** for rare and complex diseases, for specialised care and for caregivers
 - > **PAC-RD** (scale for RD patients) and **CAC-RD** (scale for RD caregivers).
 - > additional questions on **emotional support, care satisfaction and diagnostic**.
6. **Dissemination of the survey from 16 December 2019 to 29 March 2020**:
 - **online** to all rare disease patients and caregivers
 - **and on-site** (posters and leaflets) in 36 participating HCPs of the 4 ERNs of the pilot.
7. **Analysis of results**: recommendations (questionnaire, survey dissemination...) and patient satisfaction.

What is a validated scale?

*"A validated questionnaire refers to a questionnaire or **scale 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 **validity.***

If no existing questionnaires are available, or none that are determined to be appropriate, it is appropriate to construct a new questionnaire.

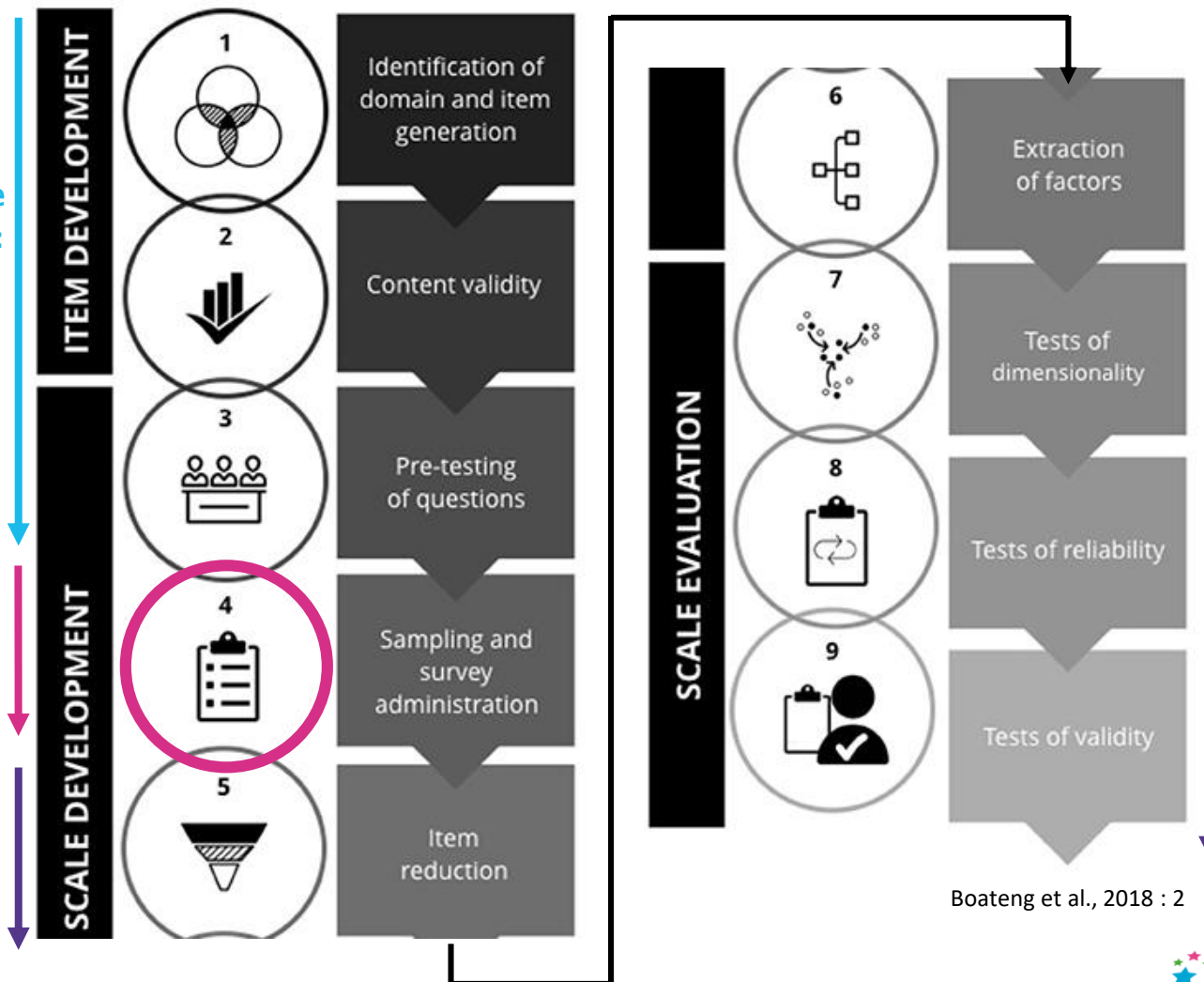
*If a questionnaire exists, but only in a different language, the task is to **translate and validate the questionnaire in the new language**"*

[Tsang, Terkawi, 2017]

9 steps to design and validate a scale

Design of the structure and wording of the questionnaire: expert committee, patients (first reading and cognitive interviews)

Survey administration (fieldwork)



Boateng et al., 2018 : 2

Questions of the PAC-RD and CAC-RD

Over the past 6 months, when [the patient] received medical care for [the patient's] rare or complex disease, I was:

1. Given choices about treatments to think about
2. Satisfied that [the patient's] care was well organized
3. Helped to set specific goals to improve [the patient's] eating or exercise
4. Given a copy of [the patient's] treatment plan*
5. Encouraged to go to a specific group or class to help me cope with [the patient's] rare or complex disease
6. Asked questions, either directly or on a survey, about [the patient's] health habits
7. Helped to make a treatment plan* that [the patient's] could do in [the patient's] daily life
8. Helped to plan ahead so I could take care of [the patient's] rare or complex disease even in hard time
9. Asked how [the patient's] rare or complex disease affects [the patient's] life
- 9b. Asked how [the patient's] rare or complex disease affects [the caregiver's] life
10. Contacted after a visit to see how things were going
11. Told how my visits with other specialists, like a geneticist or cardiologist, helped [the patient's] treatment

** A treatment plan is a list, made with your care team, of what needs to be done to take care of your health.*

Additional questions

Over the past 6 months, would you say that the health care professionals of the unit you are assessing:

- 12. Helped [the patient] deal with emotions related to [the patient's] health status
- 12b. Helped [the caregiver] deal with emotions related to the health status [of the patient]

Regarding the care you received over the past 6 months in the unit you are assessing, are you satisfied with:

- 13. The outcomes of [the patient's] care and/or treatments
- 14. The information you had on the benefits and risks of [the patient's] care and/or treatments
- 15. All in all, the care [the patient's] received in this unit

Questions on diagnostic

How long after you first sought medical advice did you get a confirmed diagnosis of a rare or a complex disease?

Was a genetic test performed before a diagnosis was given or to confirm a diagnosis?

+ gender, age, country, hospital assessed, unit assessed, diagnosed or not, disease (linked to Orphacode), how respondents heard about the survey.

Some results of the H-CARE Pilot Survey

3699 total respondents in Europe.

605 respondents in the 4 ERNs of the Pilot.

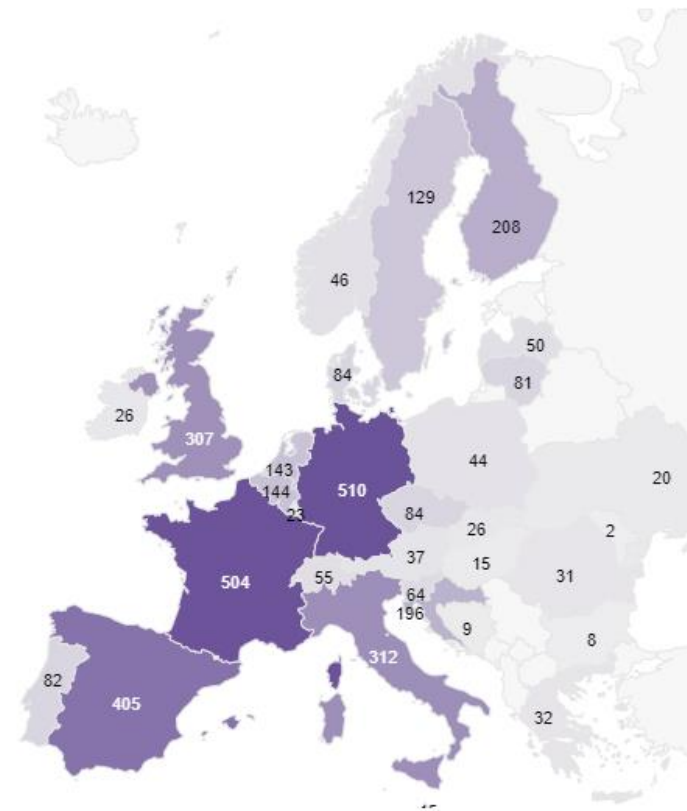
36 HCPs participating in on-site dissemination (posters and leaflets in hospitals; emails to patients when possible).

Comparison between ERN and non-ERN units

Compared to respondents who evaluated units that are not part of ERNs, respondents who evaluated HCPs of the 4 ERNs of the H-CARE Pilot Survey:

- have a significantly **better experience with their care**.
- are significantly **more satisfied with their care**.

This is true for **all items**, except for those that are **specific to caregivers**, which are low for both ERN HCPs and for non-ERN units.



Number of respondents
(country of the hospital assessed)

ePAG grouping (= disease grouping)

Possible reasons for differences between ePAG groupings:

- It may reflect **actual differences in experience with care** in the different disease groups.
- The 4 ERNs of the Pilot Survey chose the validated scale: the PAC-RD and CAC-RD **may be more adapted** to their corresponding disease groupings.
- The survey was disseminated **on-site in HCPs** of the 4 ERNs of the H-CARE Pilot; those HCPs have the **highest scores** and it probably introduces a bias when their corresponding disease groupings are compared with others.
- Some diseases may have a lower grade for some **specific items**, which lowers the average grades for the whole scales.

For instance, this can be the case for some disease groupings where there may be fewer access to **treatments**, so respondents may have answered “(1) None of the time” or “(2) Some of the time” more often to questions on treatments and treatment plans > see next slide.

Recommendations on questionnaire

1

USE A VALIDATED SCALE

1a. Ensure that cognitive testing and psychometric properties comply with international scientific standards and especially that survey dissemination allows to have at least **300 respondents per language** in which the scale should be validated.

1b. Favour analysis that are **the most useful to the different stakeholders**: ensure enough respondents per HCP and allow comparison with non-ERN units.

2

DEVELOP AND/OR FULLY VALIDATE A SCALE FOR RARE AND COMPLEX DISEASES

2a. Develop and validate a scale for rare and complex diseases.

2b. If resources, time and budget don't allow to develop and validate a scale for rare diseases, **use the scales of the H-CARE pilot survey.**

Recommendations on survey dissemination

1

TAKE INTO ACCOUNT THE SPECIFICITIES OF ERNs, MEMBER STATES AND HOSPITALS IN DISSEMINATION STRATEGY

- 1a.** Define criteria to select 10 HCPs in each of the 13 disease groups for which online dissemination does not ensure enough respondents: bone, cancers (adult and paediatric), cardiac, craniofacial and ENT, epilepsies, eye, gastrointestinal, genetic tumour risk syndromes, hepatic, renal, urogenital and vascular.
- 1b.** Continue to adapt the Rare Barometer framework to code units for the 24 ERNs.
- 1c.** Based on 3b, take into account the representation of each ERN in the Rare Barometer database to **define sampling criteria for HCPs of disease groups that are not cited in 3a.**
- 1d.** Plan coordination time with HCPs before starting survey dissemination in order to allow them to take into account specific legislations (Norway) or to coordinate with other hospital services (direction, legal services, communication, patient satisfaction, quality...).

Recommendations on survey dissemination

2

FAVOUR ONLINE DISSEMINATION

2a. Continue to disseminate online through EURORDIS channels, patient organisations and social media.

2b. Encourage HCPs to send **emails** to patients, when possible.

3

CHANGE ON-SITE DISSEMINATION STRATEGY

3a. Test the possibility for hospital staff to distribute **paper questionnaires and pre-paid envelopes**.

3b. **Centralise** the organisation of the printing and sending of all the material for on-site dissemination.

3c. Test the possibility to **extend on-site dissemination period** for HCPs to have more time to reach more respondents.

3d. Encourage more **HCPs** to participate.

Thank you!