

SETTING STANDARDS OF CARE QUALITY!

Experience and satisfaction with care of people living with a rare kidney disease in Europe

September 2020

European Reference Networks (ERNs) bring together experts from across the European Union to ensure that people living with rare or complex diseases can benefit from the best treatment and advice available for their condition. ERNs ErkNet, eUROGEN, Genturis and LUNG with the support of

Rare Barometer, have set up the H-CARE Pilot Survey to test the development of a Common Feedback Mechanism that would allow to take into account patients' and carers (family members..) experience with the care delivered by healthcare providers when evaluating the 24 ERNs.



296 PATIENTS AND CARERS

assessed European healthcare providers treating rare kidney diseases




CARE EXPERIENCE IS BETTER

with ErkNet healthcare providers than with other kidney healthcare providers


WITHIN THIS REPORT YOU WILL FIND:

1



A description of the validated questionnaire used in the H-CARE Pilot Survey and how it could be improved to measure experience and satisfaction with care in the 24 ERNs

2



Key results on care experience within European kidney healthcare providers that are part of ErkNet and that are not part of ErkNet

3



Insights on how to implement a Common Feedback Mechanism on patients' and carers' experience with care across the 8000+ rare diseases, across the 24 ERNs and across Member States

This is an initiative of:



Genetic Tumour Risk Syndromes (ERN GENTURIS)



ERN-LUNG
European Reference Network
For rare respiratory diseases



eUROGEN
European Reference Network
Urogenital Diseases

Supported by:



USING A VALIDATED QUESTIONNAIRE

A Topic Expert Committee composed of patient representatives, clinicians and managers from ERNs ErkNet, eUROGEN, Genturis and LUNG decided to use a validated questionnaire to measure experience with care in the H-CARE Pilot Survey.

Validated questionnaires are used to measure qualitative and subjective concepts, such as anxiety or care experience, through a **fixed series of questions** (or items) that are all related to the concept being measured and that are **combined to give a numerical score**. That is why validated questionnaires are also called **validated scales**.

Because there is no validated questionnaire to measure experience with care for rare and complex diseases, the H-CARE Survey Topic Expert Committee decided to use the **PACIC-S**, which is the short form of the Patient Assessment of Care for Chronic Conditions (or PACIC) questionnaire. The PACIC was developed in 2004 to measure the care experience of patients living with chronic conditions. It allows to measure how much, on a scale from 1 to 5, patient experience with care corresponds to the **Chronic Care Model**. This model was developed by the MacColl Centre for Health Care Innovation and identifies six elements that are essential for a health care system to encourage high-quality chronic disease care

Table 1. Mean score for items and scales of the H-CARE Pilot Survey (ErkNet: N =142)

	Item number	Items of the H-CARE Pilot Survey	N	Mean (sd) 1-5**
Questions (items) of the PAC-RD and CAC-RD	1	[I was] Given choices about treatments to think about	127	3.5 (1.5)
	2	[I was] Satisfied that my / the patient's care was well organized	140	4.5 (0.7)
	3	[I was] Helped to set specific goals to improve my / the patient's eating or exercise	135	3.6 (1.4)
	4	[I was] Given a copy of my / the patient's treatment plan*	129	3.8 (1.7)
	5	[I was] Encouraged to go to a specific group or class to help me cope with my / the patient's rare or complex disease	128	2.3 (1.5)
	6	[I was] Asked questions, either directly or on a survey, about my / the patient's health habits	136	3.5 (1.5)
	7	[I was] Helped to make a treatment plan* that I / the patient could do in my / his / her daily life	124	3.6 (1.5)
	8	[I was] Helped to plan ahead so I could take care of my / the patient's rare or complex disease even in hard time	123	3.5 (1.6)
	9	[I was] Asked how my / the patient's rare or complex disease affects my / the patient's life	130	3.4 (1.5)
	9C	[I was] Asked how the patient's rare or complex disease affects my [the carer's] life	54	3.4 (1.5)
	10	[I was] Contacted after a visit to see how things were going	128	2.9 (1.7)
11	[I was] Told how my visits with other specialists, like a geneticist or cardiologist, helped my / the patient's treatment	126	3.4 (1.6)	
Overall care experience	PAC-RD	Patient Assessment of Care for Rare Diseases (11 items)	59	3.0 (1.1)
	CAC-RD	Carer Assessment of Care for Rare Diseases (12 items)	44	4.1 (0.9)
Other items of the H-CARE Pilot Survey	12	[Healthcare professionals] Helped me / the patient deal with emotions related to my / his / her health status	125	3.3 (1.5)
	12C	[Healthcare professionals] Helped me [the carer] deal with emotions related to the patient's health status	53	3.5 (1.5)
	13	[I was satisfied with] The outcomes of my / the patient's care and/or treatments	136	4.3 (1.0)
	14	[I was satisfied with] The information I had on the benefits and risks of my / the patient's care and/or treatments	134	4.1 (1.1)
	15	[I was satisfied with] All in all, the care I / the patient received in this unit	133	4.4 (1.0)

* A treatment plan is a list, made with your care team, of what needs to be done to take care of your health.
 ** 1=None of the Time; 2=A Little of the Time; 3=Some of the Time; 4=Most of the Time; 5=Always
 N = number of respondents; Mean = average score on a scale from 1 to 5; sd = standard deviation.
 Questions 9C and 12C were only asked to carers.

Table 2. Model fit and internal consistency of the PAC-RD in four languages (all respondents N=3699)

	Number of respondents	Internal consistency Cronbach's α	Model fit					Sum up model fit
			Confirmatory factor analysis based on polychoric correlation matrix					
			χ^2 for independent model (df=55)	SB χ^2 (df=44)	RMSEA	CFI	AGFI	
Value good if	> 300 > 200	$\alpha > 0.9$	$p < 0.001$ $p < 0.005$	$p < 0.001$ $p < 0.005$	< 0.05 < 0.08	> 0.99 > 0.95	> 0.99 > 0.95	
German	359	0.900	7459.66 $p < 0.001$	70.550 $p = 0.0068$	0.041	0.996	1.000	Very good
French	313	0.918	9782.422 $p < 0.001$	89.785 $p < 0.001$	0.058	0.995	1.000	Good
English	309	0.937	14969.99 $p < 0.001$	127.121 $p < 0.001$	0.078	0.994	1.000	Good
Spanish	201	0.941	11446.697 $p < 0.001$	81.017 $p = 0.0006$	0.065	0.997	1.000	Good

Colour code for values

KEY RESULTS ON CARE EXPERIENCE

ErkNet results regarding experience with care are encouraging

Table 3. Mean score for the PAC-RD and CAC-RD, on a scale from 1 to 5

3.5	Average care experience of patients and carers with ErkNet healthcare providers. <i>In the scientific literature on chronic conditions, the highest scores for the PACIC questionnaire are 3.3, which are mostly reached when care teams are multidisciplinary or trained for chronic care and when patients are part of a disease-management program¹.</i>
3.0	Average care experience of patients and carers with kidney healthcare providers that are not part of ErkNet. <i>This score is significantly lower than the average score for ErkNet healthcare providers.</i>

Compared to respondents who evaluated kidney healthcare providers that are not part of ErkNet, respondents who assessed ErkNet healthcare providers

Table 4. Sample characteristics

Healthcare providers (HCPs) assessed in the H-CARE Pilot Survey that are part of ErkNet	Kidney healthcare providers (HCPs) assessed in the H-CARE Pilot Survey that are not part of ErkNet
142 respondents.	154 respondents.
6 in 10 respondents were contacted through their care team.	10 in 10 respondents contacted online (50 % patient organisations; 30% EURORDIS channels).
9 participating HCPs, that received individualised results.	Kidney HCPs that are not part of ErkNet did not disseminated the survey on-site.
9 in 10 respondents assessed 3 HCPs (Paris, Barcelona and Vilnius), hence country breakdown (see map 1).	Less country-specific (see map 2).
6 in 10 respondents are patients.	7 in 10 respondents are patients.
2 in 10 respondents are below 25 years old.	Less than 1 in 10 respondents are below 25 years old.
2 in 3 respondents are women.	2 in 3 respondents are women.
Less disease-specific	

DEVELOPING A COMMON FEEDBACK MECHANISM

The H-CARE Pilot Survey allowed to better understand how to **set standards of care quality for rare diseases** and **how to develop a Common Feedback Mechanism** to measure patients' and carers' experience with care across the 8000+ rare and complex diseases, across the 24 ERNs and across Member States.

Based on key results presented above, the H-CARE working group will propose a project that would allow to