

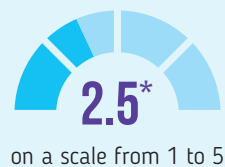
# IMPROVE OUR EXPERIENCE OF HEALTH CARE!

3905 people living with rare diseases expressed their views on their experience of medical care through the H-CARE Survey conducted by EURORDIS-Rare Diseases Europe between December 2019 and March 2020

## 1 THE HEALTHCARE EXPERIENCE OF PEOPLE LIVING WITH A RARE DISEASE

Rare disease patients give their healthcare experience a medium-low score

Rare disease patients on average rate their healthcare experience...



Rare disease patients seem to have a worse experience of health care than patients with chronic diseases: 70% of studies that used the same questionnaire reported a higher average score for chronic disease patients' experience of health care\*\*.



The score for rare disease patients' healthcare experience was obtained by combining answers to 11 questions related to follow-up after consultations, information on treatments, care coordination or how to manage their health in their daily life.

To ensure a better healthcare experience the top 3 areas that need to be improved are:

1



Contacting patients or carers after a visit to see how things are going

2



Encouraging patients or carers to go to a specific group or class to help them cope with the rare disease

3



Helping patients and carers deal with emotions related to the patient's health status



Over the past 6 months, when I/the person I care for received medical care for my/his/her rare disease, I was:

\* Average score on a scale from 1 (never) to 5 (always).

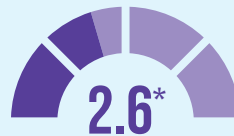
\*\* Based on the results of 52 peer-reviewed studies using the PACIC or the PACIC-S questionnaires. These questionnaires were developed by the MacColl Centre for Health Care Innovation to measure the healthcare experience of chronic disease patients.

## 2 THE CRUCIAL ROLE OF CENTRES OF EXPERTISE FOR RARE DISEASES

Patients and carers living with a rare disease affecting kidneys, lungs, the urogenital area and genetic tumour risk syndromes have a better healthcare experience when they are treated by hospital units that are part of a European Reference Network\*\*\*

Typically, hospital units that are members of a European Reference Network are Centres of Expertise that bring together **multidisciplinary care teams specialised in the treatment of a given rare or complex disease**. Further research is needed to measure differences in healthcare experience depending on the type of hospital unit for other rare disease areas.

On a scale from 1 to 5, rare disease patients' and carers' average experience of health care receives a rating of...



when patients are treated in hospital units that are...

✓ **PART**  
of a European  
Reference Network

(centres of expertise for rare diseases)

✗ **NOT PART**  
of a European  
Reference Network

Chronic disease patients also report a better experience of health care when their care team is multidisciplinary or trained in chronic care and when they are part of a disease-management programme\*\*.



The score for average healthcare experience was obtained by combining answers to 11 questions (for patients) or 12 questions (for carers) related to follow-up after consultations, information on treatments, care coordination or how to manage their health in their daily life.

\*\*\*[ec.europa.eu/health/ern\\_en](http://ec.europa.eu/health/ern_en)

For more information on the questions of the survey, on its results and on recommendations, [see the complete factsheet](#) or contact [rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org)

### THANK YOU

to all people living with a rare disease who participated in the survey, to the healthcare providers and patient representatives of the European Reference Networks ErkNet, eUROGEN, LUNG and Genturis who participated in the design and the dissemination of the H-CARE Survey, and to Rare Barometer partners!



A EURORDIS INITIATIVE

EURORDIS-Rare Diseases Europe regularly surveys the rare disease community via its Rare Barometer programme to identify patients' perspectives and needs on a number of issues in order to be their voice within European and International initiatives and policy developments. Rare Barometer brings together over 15,000 patients, carers and family members to make the voice of the rare disease community stronger. For more information visit [eurordis.org/voices](http://eurordis.org/voices).