

Partners & Collaborators



FINANCED BY:



Discover who we are

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Health Services Research

www.sciensano.be

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Want to learn more about rare diseases?

Orphanet (www.orpha.net) is the international portal dedicated to rare diseases. This website provides scientific information on more than 6,400 known rare diseases, accessible to all audiences.

Orphanet also offers information on specialized services, such as patient organizations, national and international research, as well as new initiatives related to rare diseases.

You can contact the Belgian Orphanet team at the following address:
orphanetbelgium@sciensano.be



Central Registry of Rare Diseases (CRRD)





RARE, BUT NOT ALONE !

In Europe, a disease is considered rare if it affects fewer than 1 in 2000 people.

But with over 6400 rare diseases, thousands of patients in Belgium are impacted.

The Central Registry of Rare Diseases (CRRD) helps us:

- ✓ Better understand how many people are affected by rare diseases in Belgium.
- ✓ Support research and help find participants for clinical trials.
- ✓ Inform decisions about healthcare policies and treatments.
- ✓ Improve care by comparing outcomes and setting quality benchmarks.

WHAT IS THE CRRD ?

The CRRD is a national database that securely collects essential information from people with rare diseases who have seen a specialist in Belgium.

This aims to help improve care, guide research, and shape better health policies.

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WHY IS THE CRRD IMPORTANT ?

The CRRD helps understand rare diseases better on a national and international level.

Right now, there's not enough information about how many people are affected or what care they need. By being part of the CRRD, you're helping to improve care, raise awareness, and make sure people with rare diseases get the support they deserve.

WHAT DATA IS COLLECTED ?

The CRRD gathers important information about patients in a way that keeps the patient's identity private.

This includes details about the diagnosis and diagnostic journey, as well as information on consultations and referrals to specialists.



WHO IS RESPONSIBLE FOR PROCESSING MY DATA?

Sciensano, a federal scientific institute, is responsible for data processing and conducts research to support health policy and the quality of care.

In addition, Sciensano also provides expertise and services in the field of public health.



HOW ARE MY DATA PROTECTED?

Your data are handled with the utmost care and the highest level of security.

Only your treating physician can access identifiable data; researchers only have access to pseudonymised data.

CRRD data are stored in pseudonymised form for up to 30 years after the patient's death.



YOUR DATA, YOUR CHOICE

The Information Security Committee (ISC) has determined that it is not necessary to obtain patient consent for registration in the CRRD (authorization according to deliberation no. 13/105).

However, you have full control over your participation. If you prefer not to share your data, simply inform your doctor.

YOUR RIGHTS

To exercise your rights as a data subject (including the rights of access, rectification, or data portability), you can contact your treating physician.

Do you have a complaint?

You can address it to your treating physician, the Data Protection Officer (DPO) via dpo@sciensano.be, or to the Data Protection Authority:

Rue de la Presse 35, 1000 Brussels, or via www.autoriteprotectiondonnees.be.