

Rare diseases: European evaluation report gives Radboud university medical center high scores

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A high level of expertise and excellently organized and assured quality of care and safety: this is how the evaluation report on European Reference Networks (ERNs) published this week assesses the Radboudumc contribution. Within the ERNs, European centers of expertise work closely together in the field of rare diseases, including case discussions. Our UMC participates in 18 ERNs. We coordinate European network activities for rare urological and oncological conditions.

The international, independent audit committee gives Radboud University Medical Center an almost maximum score on seven important sub-topics. This includes patient-oriented care, knowledge exchange, research & education and 'general competence, experience and care outcomes'. Quality & safety, personnel deployment (HR) and organizational aspects also receive high ratings. According to

the assessment, Radboud University Medical Center collaborates excellently with European partner hospitals and used the right e-health systems to provide remote care. This makes teleconsultation possible, for example, so that healthcare professionals can discuss cases 'internationally'. Kudos are also due for organizing and guaranteeing quality and safety. The audit team further states that internationally agreed guidelines are properly followed and appreciates the 'high level of expertise' of our healthcare professionals.

Points of improvement

Of course, there is always something to improve: although the use of digital facilities and online tools receives a good rating, the use of the Clinical Patient Management System (CPMS) could be improved, according to the evaluation report. Through this CPMS, practitioners submit cases to colleagues in other participating hospitals. "Our experts in the field of rare diseases are regularly consulted via this platform and vice versa," explains policy advisor for expertise centers and ERNs Yvonne van Vugt. 'But I hear from healthcare providers that it takes a lot of time and administration and that the CPMS is not experienced as user-friendly. In many cases there is no compensation in return: a lot of ERN work has to be done in 'your own time'. So then you want a handy tool. Fortunately, there will be a new one next year,

Another area for improvement concerns the services for international, non-Dutch-speaking patients. This point will be further addressed together with the RIPO (Radboud International Patient Office).

Praise

In broad terms, the audit team is very complimentary about all the efforts made by Radboud university medical center for the ERNs. This certainly also applies to GENTURIS and eUROGEN, the two networks coordinated by our UMC. 'Impressive quality of the network', 'highly specialized and passionate professionals' and 'excellent collaboration with other ERNs, institutions, patient representation, patient organizations and scientific associations', the report states. Special praise goes to the active involvement of patients.

The evaluation shows that not all participating centers are at the same level: the difference in level between countries and individual centers is quite large, the rapporteurs say.

Good road

European regulations require that the ERNs, including all participants, must be evaluated every five years. "For now, the evaluation report is proof that we are on the right track," says Yvonne van Vugt. 'A great boost for everyone who is committed to the ERNs.'

Radboud university medical center is involved in 18 of the 24 European reference networks. Four recently started ERN participations were excluded from the evaluation.

What does it benefit 'the patient'?

What benefit does an ERN serve for patients? The list below shows what ERN GENTURIS has achieved so far, directly within healthcare or indirectly through, for example, sharing knowledge. ERN GENTURIS is coordinated by [Radboud university medical center professor and internist-oncogeneticist Nicoline Hoogerbrugge](#) . For other ERNs the numbers will differ, but many themes are the same.

- approximately 9,000 patients (annually) seen within the entire ERN
- multidisciplinary advice to 200 complex European patients (with active input from Radboud university medical center)
- 7 new European guidelines
- 13 existing guidelines assessed and adopted ERN-wide
- description of 7 new care pathways as a guideline for doctors
- 46 online lectures for healthcare providers, available free of charge as further training
- further training courses for clinical geneticists and medical oncologists
- 8 joint, successful scientific research projects (in rare diseases often only possible through network collaboration).

About ERNs

European Reference Networks are virtual networks of hospitals from all over Europe, focused on rare diseases. Through ERNs, patients can gain more frequent and faster access to expert expertise and care. The participating expertise centers join forces in terms of expertise, guideline development, education, training, further education and innovation, scientific research, clinical trials and registration. More information about the Radboud university medical center ERNs [can be found here](#) .

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