



Q&A Factsheet: 5-Year Evaluation of the European Reference Networks

In the next 12 months, the **European Reference Networks (ERN)** and the **Healthcare Provider (HCP) Members** will be evaluated an **Independent Evaluation Body (IEB)**, who is appointed by the **European Commission (EC)**. As the ERNs are patient-centred networks, the ERN Evaluation Manual and Toolkit, recognises the important role of patients and patient groups in the ERNs. Patient representatives are recognised as key stakeholders in the ERNs and will play an important part of this evaluation. This Factsheet aims to inform the patient representatives in the ERNs about the evaluation and specifically explain their role.

Q1. WHY ARE THE ERNS BEING EVALUATED?

The Networks are required under EU law to be evaluated on a regular basis, and as a minimum before the end of the first 5-year contractual period.

Q2. WHAT WILL BE THE FOCUS OF THE EVALUATION OF THE NETWORKS?

The evaluation will focus on assessing four key topics:

- ✓ To check if the Networks and the HCP Members continue to fulfil the requirements set out in the EU law.
- ✓ To evaluate to what degree the Networks have achieved the original objectives which were set out in their application.
- ✓ To evaluate the outcomes and performance of the Network and the contribution of each HCP Member.
- ✓ The achievement of the objectives and quality of the deliverables produced with under the Network's grants with the EC.

Q3. WHO WILL BE EVALUATED?

All 24 Networks will be evaluated as well as the **HCP Members** of the networks who joined under the first call and at the launch of the Networks in 2017 (c.900). The HCP Members who joined the Networks in January 2022, under the second call for applications in 2019 are exempt from this evaluation.

Q4. WHEN WILL IT TAKE PLACE?

The expected timeline for the ERN 5-yr Evaluation is expected to start in September/October 2022 and the evaluation reports completed in August 2023.

Q5. HOW WILL THE EVALUATE BE ORGANISED FOR THE NETWORKS?

The Network will first complete a self-evaluation against a set of 'evaluation criteria' and provide supporting evidence to their self-assessment. Next, the IEB will complete a documentation review of the self-evaluation and the supporting evidence, to identify key areas for discussion with the network. Finally, the IEB will conduct some interviews with the coordinators and leads of the Networks to discuss the achievements of the networks and any areas that require further clarification.

Q6. WHO IS INVOLVED IN THE EVALUATION PROCESS FOR THE NETWORKS?

Coordinators of the Networks and European Union (EU) Funded Projects; Chairs of the Networks' groups defined under their governance structure; and Patient Representatives.

Q7. WHICH PATIENT REPRESENTATIVE WILL BE SELECTED TO BE INTERVIEWED?

As the IEB will conduct interviews with the coordinators and chairs of the Networks' groups, we believe that patient representatives who have been in the Networks since their launch and who sit on the ERN Board, Executive Committee or Co-Chairs of the Sub-Thematic Networks will be selected. However, the selection criteria and process aren't defined in the evaluation process.

Q7. WHAT WILL BE THE ROLE OF PATIENT REPRESENTATIVES (ACTIVE IN THE ERNS) IN THE EVALUATION PROCESS?

The focus of patient representatives' involvement in the evaluation will be specifically to give the patient's perspective on four main elements:

- ▶ The structure for patient involvement in the Networks and its effectiveness
- ▶ The impact of patient involvement in the strategic discussion and operational actions
- ▶ The main barriers and enablers for meaningful patient involvement in the Network
- ▶ Your reflections regarding the whole ERN system, in particular the extent the Network has accomplished the objectives and the achievements of the Network

Q8. HOW WILL THE INTERVIEWS WITH PATIENT REPRESENTATIVE BE ORGANISED AND HOW LONG WILL IT TAKE?

A separate interview with patient representatives will be organised. The ERN Coordinators will facilitate communication between the IEB and the patient representatives for the interview. The interviews are expected to last less than 2-hrs and will be confidential.

Q9. WHAT SHOULD THE PATIENT REPRESENTATIVES DO NOW TO PREPARE?

The evaluation team will prepare and share the interview script and questions ahead with the patient representatives. The patient representatives who will be interviewed should spend time reflecting on the questions and can also discuss these questions with the patient group in the Network, in order to understand the views of the other patient representatives active in the Network.