



The first 5 years of ERNICA

An overview of key achievements

Period: 2017 until 2022

The European Reference Network for rare Inherited and Congenital Anomalies (ERNICA) was launched in March 2017 by the European Commission. ERNICA is coordinated by the Erasmus Medical Centre in Rotterdam, the Netherlands.

This report aims to provide an overview of key achievements during the first five years of ERNICA. ERNICA cannot exist without the contributions of its members, and our achievements over the past five years are a promising sign for the future.

Do you have any questions about this report? Feel free to reach out to the ERNICA project management team: ern-ernica@erasmusmc.nl.

GOVERNANCE AND COORDINATION

✓ The ERNICA statute ('rules of procedure') has been developed and kept up to date. This provides information on ERNICA (its background, aims and objectives, legal base and disease coverage), membership and partnership, governance (including organisational structure and roles and responsibilities) and budget and funding.

✓ **20** hospitals from 10 different countries became **full members** of ERNICA in 2017. Following a second call in 2019, **21** new hospitals across three additional countries joined in 2022. In March 2022, ERNICA had a total of 40 member hospitals across 12 EU/EEA countries.

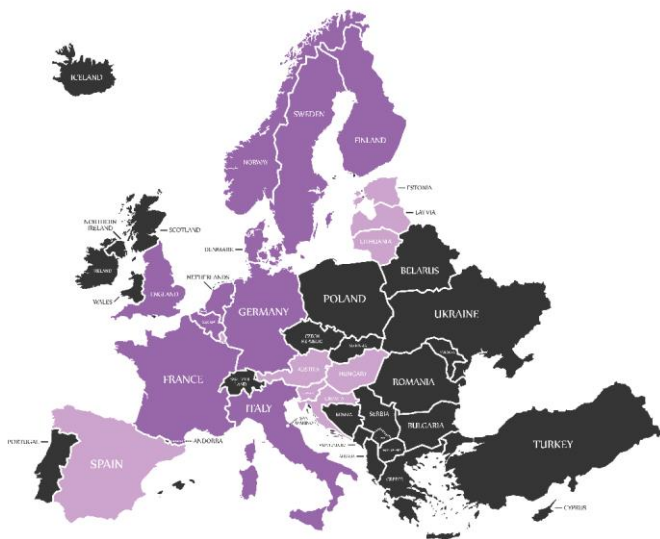
✓ In 2020, 17 hospitals were accepted as **affiliated partners** of ERNICA. This was subsequently reduced to 13 in 2022, as a result of three hospitals becoming full members in 2022 and one termination.

✓ Involvement of **multidisciplinary clinicians and patient representatives** in the ERNICA governance structure and ERNICA-related tasks.

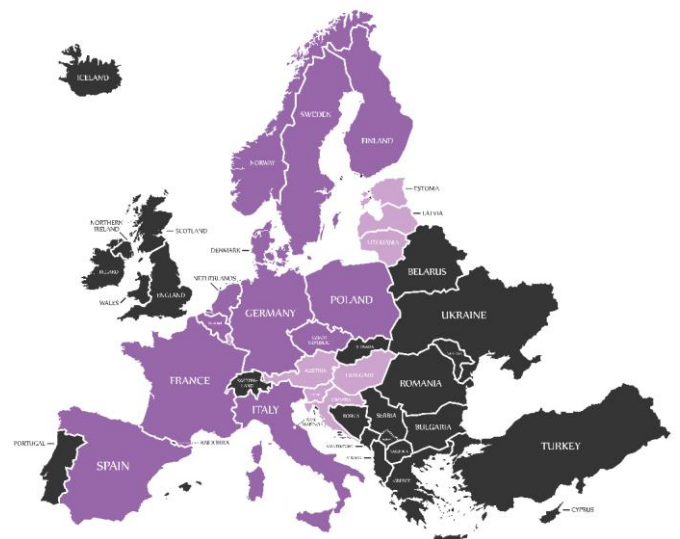
✓ **Patient representatives/groups have been major stakeholders in ERNICA related activities.**

✓ **ERNICA has collected performance data** from participating centres, helping to build a quality improvement system, define appropriate ERN outcomes, identify areas of success and potential pitfalls and demonstrate the value of the ERNs, by learning from experience.

*Countries with full ERNICA members involved (Purple) and countries with affiliated partners involved (Lilac) **2017***



*Countries with full ERNICA members involved (Purple) and countries with affiliated partners involved (Lilac) **2022***



✓ Various mechanisms and strategies have been used to promote **collaboration** between ERNICA members and affiliated partners:

- Annual network meetings
- ERNICA board meetings
- Disease-group/project group/committee (lead) meetings
- Introductory session for new members/affiliated partners
- Organisation / endorsement of ERNICA training events/courses
- Surveys
- Clinical/Data platforms
- Dissemination tools

PATIENT-CENTRED CARE



✓ **Animation videos for patients and families:** A total number of 17 educational resources have been developed for patients/parents during the first 5 years of ERNICA. All of the videos were co-designed with patient representatives, parents or patients. These videos have been translated into different languages.



✓ **Patient versions of guideline/consensus statements:** ERNICA has published three summary versions of consensus statements on Esophageal Atresia and Tracheoesophageal Fistula with specific information relevant to patients and families.



✓ **ERNICA sexual support website:** ERNICA extended its public website to include a dedicated section on sexual support for patients with Hirschsprung's Disease and Anorectal Malformations, available in English and Dutch.



✓ **The ERNICA paediatric intestinal failure map tool for travelling abroad:** this map tool enables patients (who are reliant on parenteral nutrition) and their families to easily search for specialist centres across Europe.

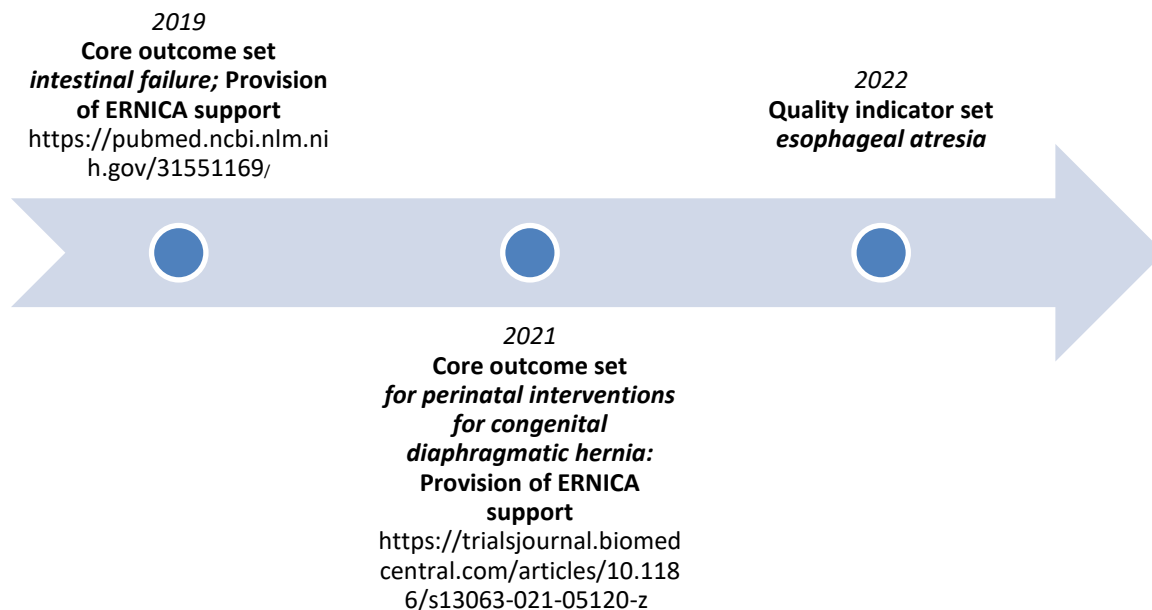
QUALITY AND PATIENT SAFETY

✓ Development of ERNICA **Patient Journeys** on the following diseases: Hirschsprung's Disease and Esophageal Atresia. A patient journey promotes better understanding of these rare congenital diseases and aims to support communication between clinicians, parents and patients. It gives an overview of symptoms, diagnosis and treatment and describes the crucial stages of life with the disease.

✓ Development of **disease-specific quality indicator set for esophageal atresia** for the EPSA/ERNICA registry.

✓ ERNICA has developed a **European patient registry** (the EPSA/ERNICA registry), building on an already established registry developed in 2014 by DICA (Dutch Institute for Clinical Auditing).

✓ Interactive ERNICA-EPSA feedback sessions took place to facilitate collective reflection, learning and improvements.

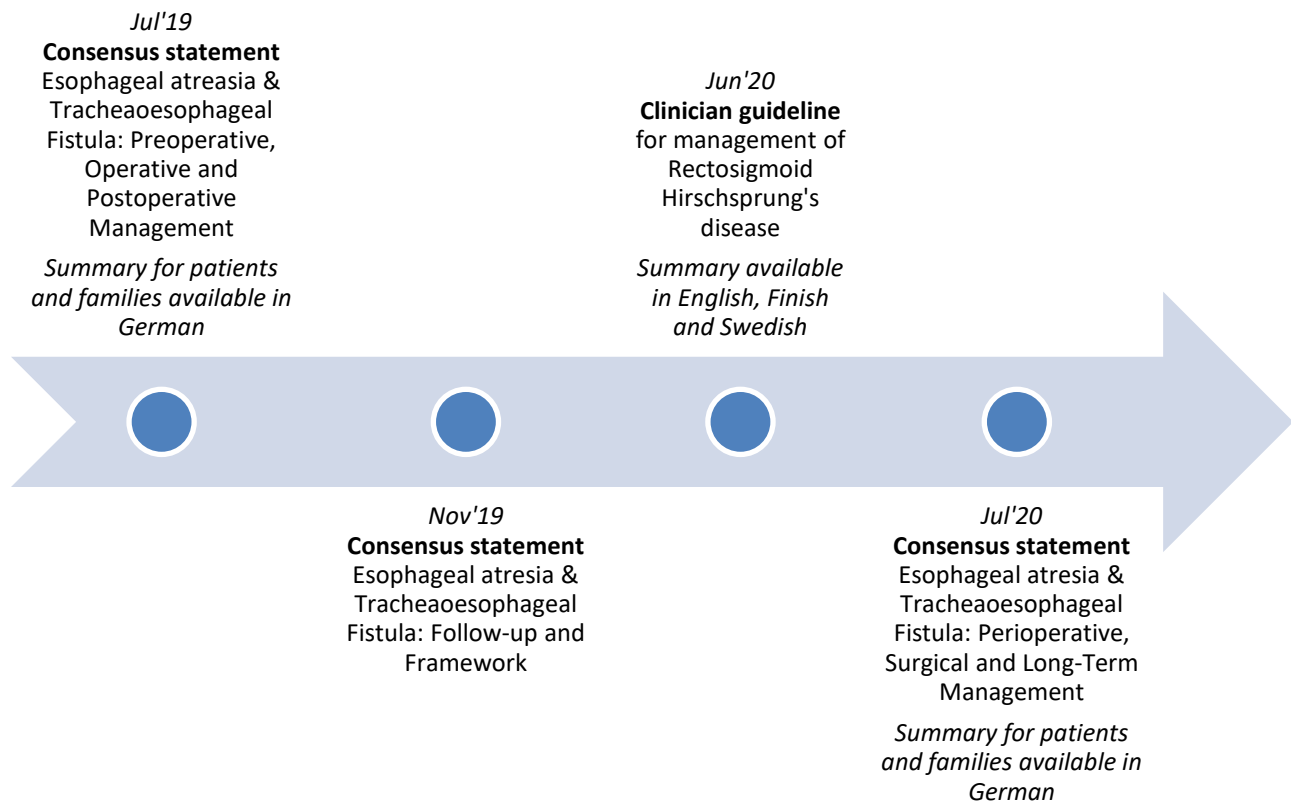


STANDARD OF CLINICAL CARE

✓ ERNICA has promoted the use of **CPMS** to discuss complex patient cases. Cross-border clinical discussions took place for 27 patients and panels of disease-group-specific experts have been established.

✓ Development of **clinical guidelines** and **consensus statements**.

✓ Development of an **ERNICA clinical summary** of the ERNICA Rectosigmoid Hirschsprung's clinical guideline.



EDUCATION AND TRAINING

✓ ERNICA has identified **education, training and professional development gaps** and has defined areas of focus for teaching and training.

✓ ERNICA launched a EUPSA-ERNICA clinical exchange programme, facilitating **clinical exchanges** for surgical trainees/fellows/consultants from within the EU (not only within ERNICA), tailored to their learning needs. The ERNICA-ECORYS exchange programme was also launched, providing the opportunity for multidisciplinary ERNICA professionals to take part in a clinical exchange.

✓ Four clinical exchange visits took place during the first five years (limited by COVID-related travel restrictions).

✓ ERNICA has organised **site visits**, for representatives to visit other European hospitals.

✓ ERNICA has collaborated on **educational webinars** with eUROGEN (10) and the European Paediatric Surgeon's Association (EUPSA) (1).

✓ ERNICA members and affiliated partners had the opportunity to order **surgical training models** ('Pedatrickboxxes') for local training purposes and ERNICA endorsed and sponsored hands-on training courses using the models.

✓ ERNICA has developed **live-surgery (recorded) videos**.

✓ ERNICA has developed & translated **animations for patients and families**.

RESEARCH

✓ **ERNICA Scientific Committee** has been established.

✓ **ERNICA research strategy pillars and themes** have been defined.

✓ Identification & prioritisation of top disease-group-specific research gaps.

✓ **ERNICA research collaborations** with other ERNs were strengthened through the European Rare Disease Research Coordination and Support Action Consortium (ERICA), the European Joint Programme for Rare Diseases (EJP-RD) and with the Research and Development Office at ERNICA's coordination centre.

✓ **Launch of first ERNICA randomised controlled trial** (STEPS-EA trial).

✓ **Submission of research grant applications and engagement in (multi-centre) research studies.**

✓ **Research overview** developed outlining the research ongoing in ERNICA centres.

NETWORKING AND DISSEMINATION

✓ ERNICA has enhanced the **collaboration with other ERNs and HCPs** to exchange and disseminate knowledge, best practices, clinical expertise, and other resources.

✓ ERNICA has developed an **affiliated partner integration strategy**.

✓ ERNICA has developed **partnerships and collaborations with other stakeholders** of interest: EURORDIS, European Joint Programme for Rare Diseases (EJP-RD), EUPSA, International Network of Esophageal Atresia (INoEA) and ESPGHAN.

✓ **Communication and dissemination strategy development.**

- Identification of target groups for communication