# EPSA European Pediatric Surgical Audit

European Reference Network for rare or low prevalence complex diseases

Network Inherited and Congenital Anomalies (ERNICA)

Registertage – April 2022

# EPSA|ERNICA Registry

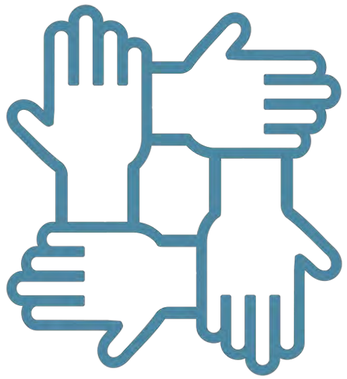
# Agenda

EPSA|ERNICA Registry – Registertage 2022

- **Purpose** and overview
- **Governance** and **structure**
- The programme: **survey**
- **Connecting** medical centers
- From **(registrative) burden** to **blessing**

# EPSA|ERNICA Registry

Context



- European Reference Networks
- European Reference Network for Inherited and Congenital Anomalies (**ERNICA**)

→ **registries**

# EPSA|ERNICA Registry

## Purpose

With clinical auditing you register your patient

Enabling comparison of process and outcomes between hospitals

Identifying areas of best practice or with room for improvement

And that can advance the quality of care!

# EPSA|ERNICA Registry

What do we register - conditions

- Esophageal Atresia
- Congenital Diaphragmatic Hernia
- Omphalocele
- Gastroschisis
- Hirschsprung's Disease
- *More to follow*

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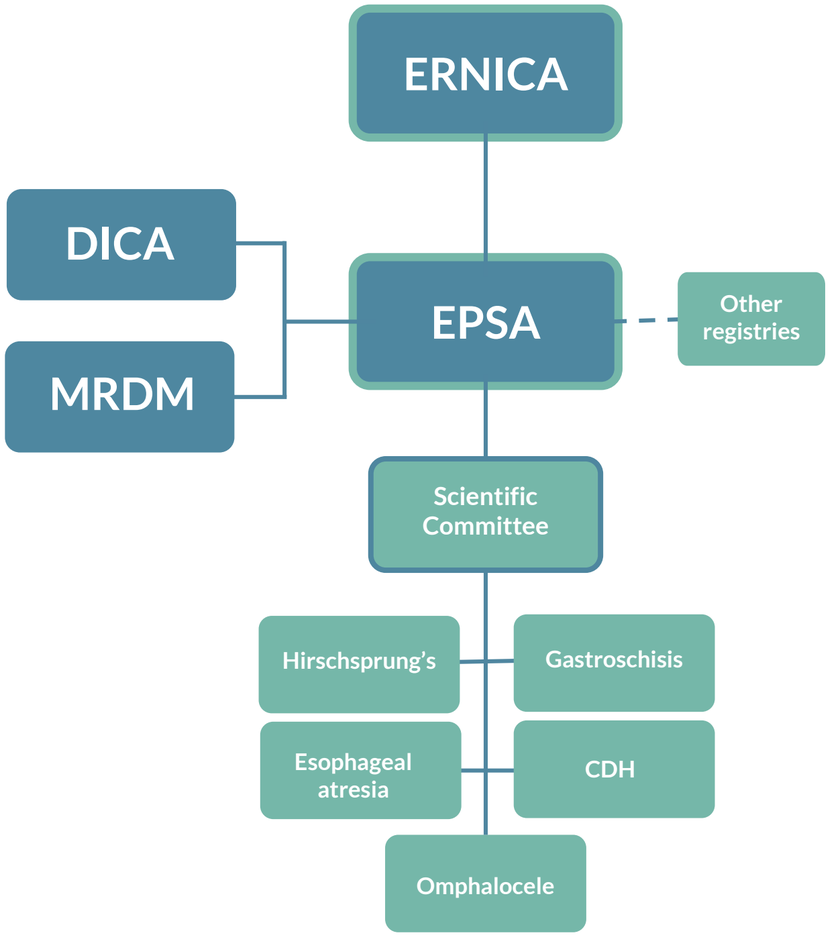


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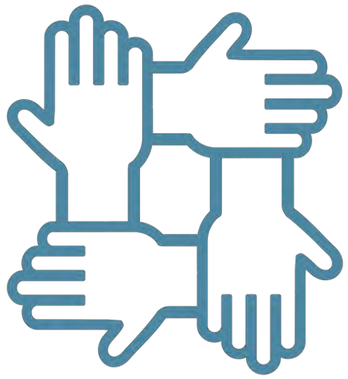
## Dutch Institute for Clinical Auditing



By clinicians for clinicians

Provide direct insight


Supporting team

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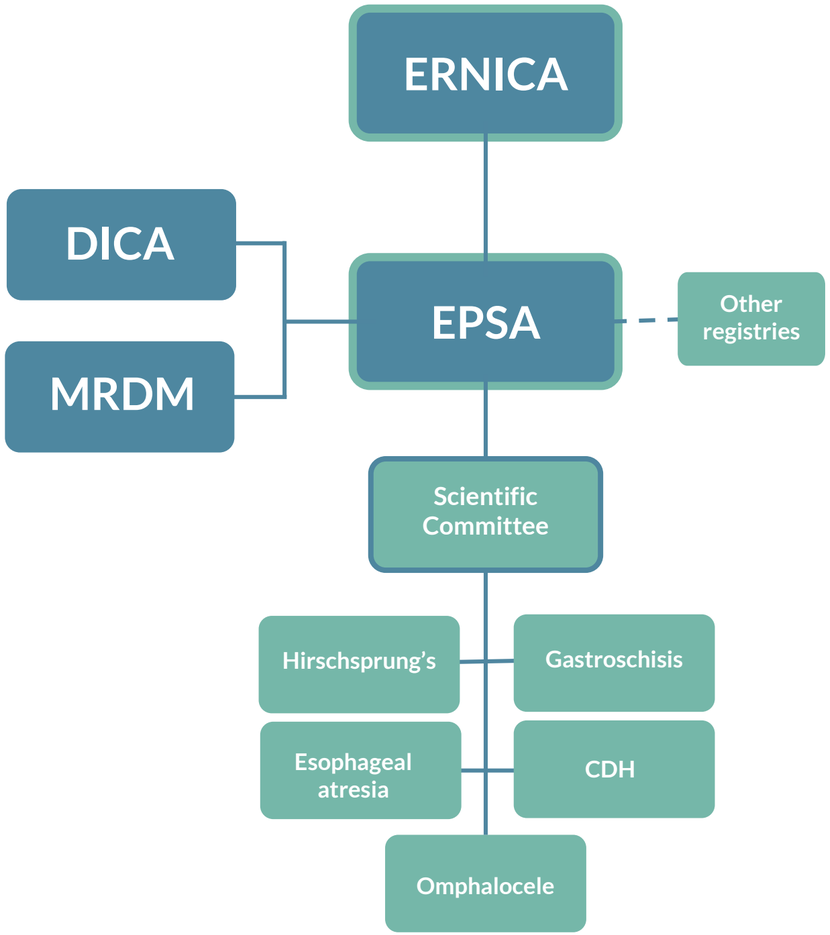


# EPSA|ERNICA Registry

The registration process

With clinical auditing you register your patient

Enabling comparison of process and outcomes between hospitals

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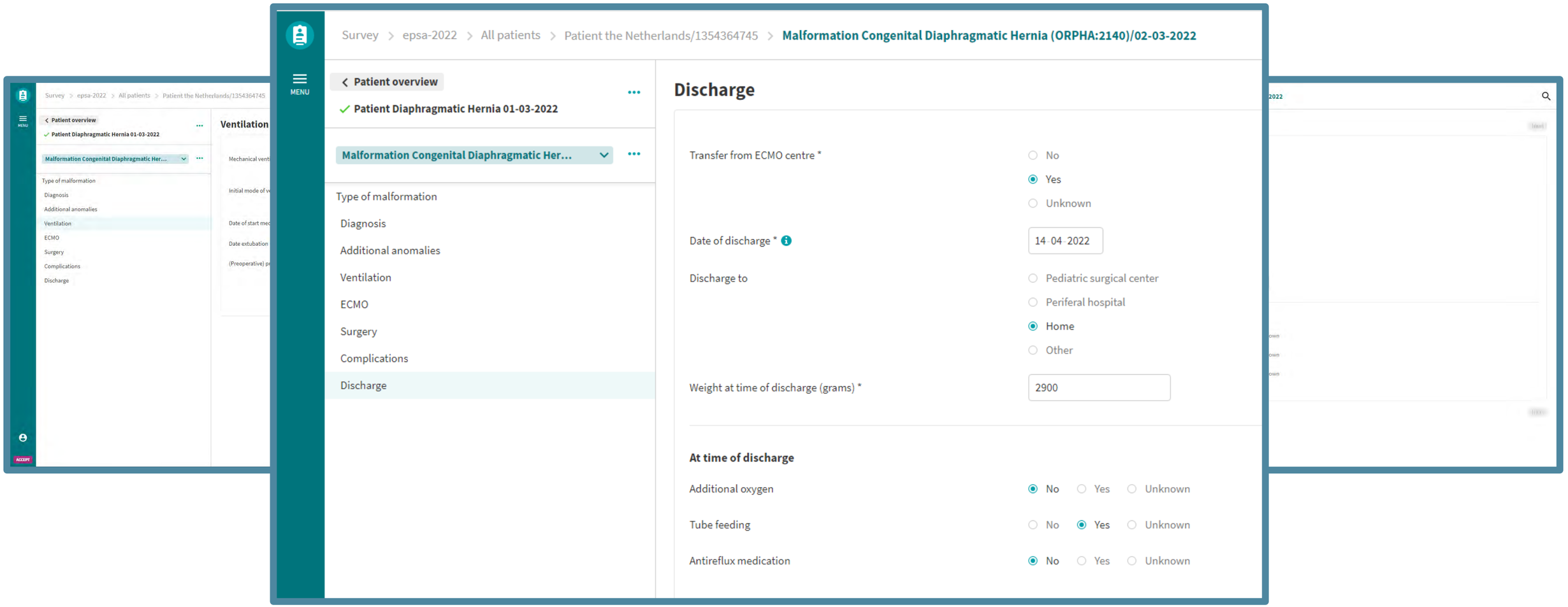
## How do we register – Survey (MRDM)



# EPSA|ERNICA Registry

## What do we register: data points

| | | |
|---|---|---|
| 1. | Number of patients operated on, seperated per disorder | Structural |
| **Anorectal malformation** | | |
| 2. | Percentage of patients that receive surgical treatment for anorectal malformation and is screened for associated anomalies (ultrasonography of the kidneys, roentgenogram of the lumbosacral vertebrae, chromosomal abnormalities (after birth) | Process |
| 3. | Percentage of patients which surgical treatment for anorectal malformation with a postoperative wound infection (grade 3 or 4) or wound dehiscence | Outcome |
| **Esophageal atresia** | | |
| 4. | Percentage of patients with esophageal atresia (type C and D) on whom ultrasonography of the kidneys is performed | Process |
| 5. | Percentage of patients with oesophageal atresia (type C and D) with postoperative leakage of the anastomosis | Outcome |
| 6. | Number of dilatations under general anesthesia in patients with oesophageal atresia (type C and D) with a suspicion of anastomotic stricture during the first year of life | Outcome |
| **Hirschsprung's disease** | | |
| 7. | Percentage of patients with Hirschsprung disease in whom temporary colostomy is given prior to or during resection of the aganglionotic segment | Process |
| **Congenital Diaphragmatic Hernia** | | |
| 8. | Percentage of patients with congenital diaphragmatic hernia that dies in the first month of life with respiratory failure without starting ECMO | Process |
| **Gastroschisis** | | |
| 9. | Median duration of the period (in days) between the first operation and full enteral feeding | Outcome |
| 10. | Percentage of patients with gastroschizis and postoperative central catheter septicaemia | Outcome |
| **Omphalocele** | | |
| 11. | Percentage of patients with omphalocele in whom consultation of clinical genetics is performed after birth | Process |
| **Biliary atresia** | | |
| 12. | Percentage of patients with biliary atresia that undergoes Kasai procedure within 60 days after birth | Process |
| 13. | Percentage of patients with biliary atresia in whom serum bilirubin has normalized (<20µmol/L), 6 months after surgery | Outcome |
| 14. | Percentage of patients with biliary atresia in whom a Kasai procedure is performed and who died without liver transplantation in the first year of life | Outcome |

- Undertaken diagnostic tests
- Associated anomalies
- Date of surgery
- Details of performed surgery (e.g. location of enterostomy, surgical approach or material used)
- Occurrence of complications (and specification hereof)
- Details of hospital admission and discharge

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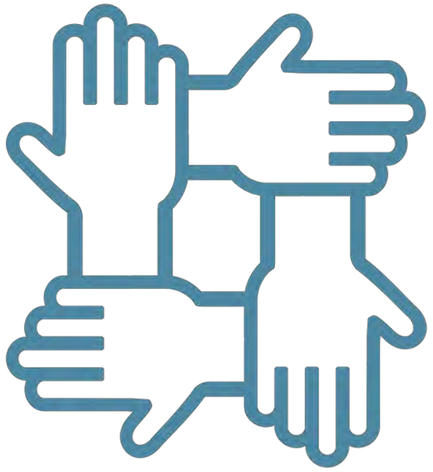
What do we measure - selecting quality indicators

**Performing a systematic literature review**

**Create a list of all possible outcome, process and structure indicators**



**Using a Delphi method to create consensus**


**Patient involvement through parallel Delphi**

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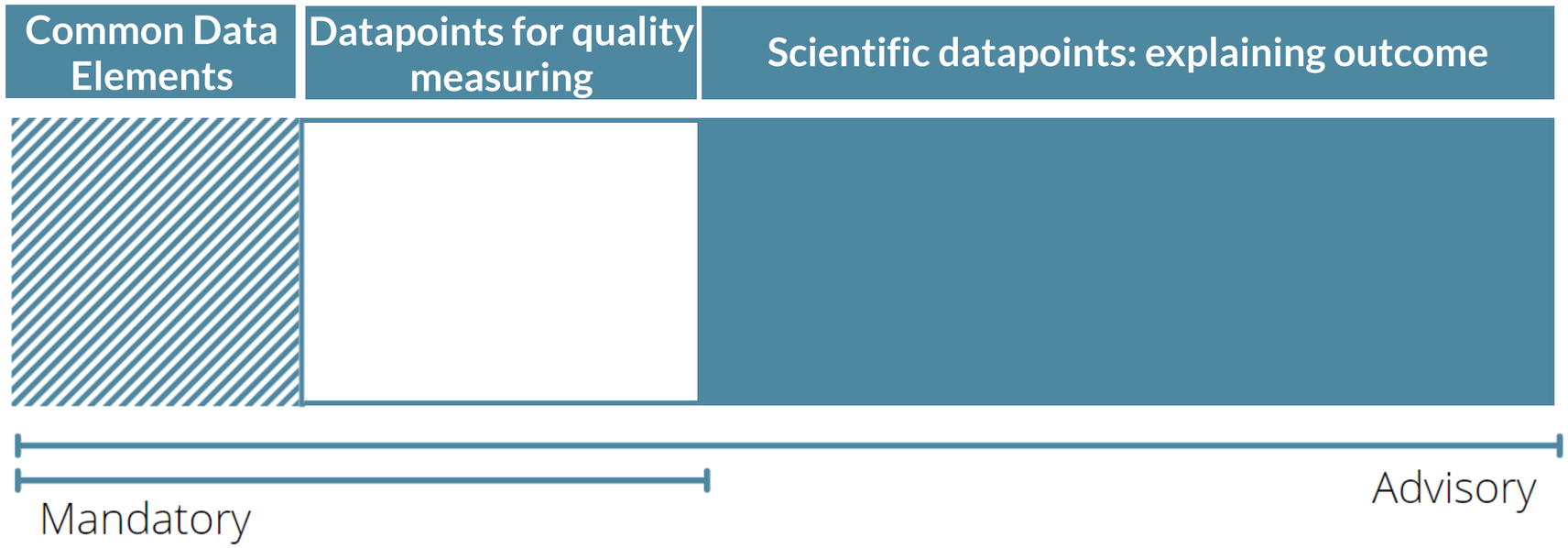
What do we register: structure dataset



# EPSA European Pediatric Surgical Audit

## Who participate?

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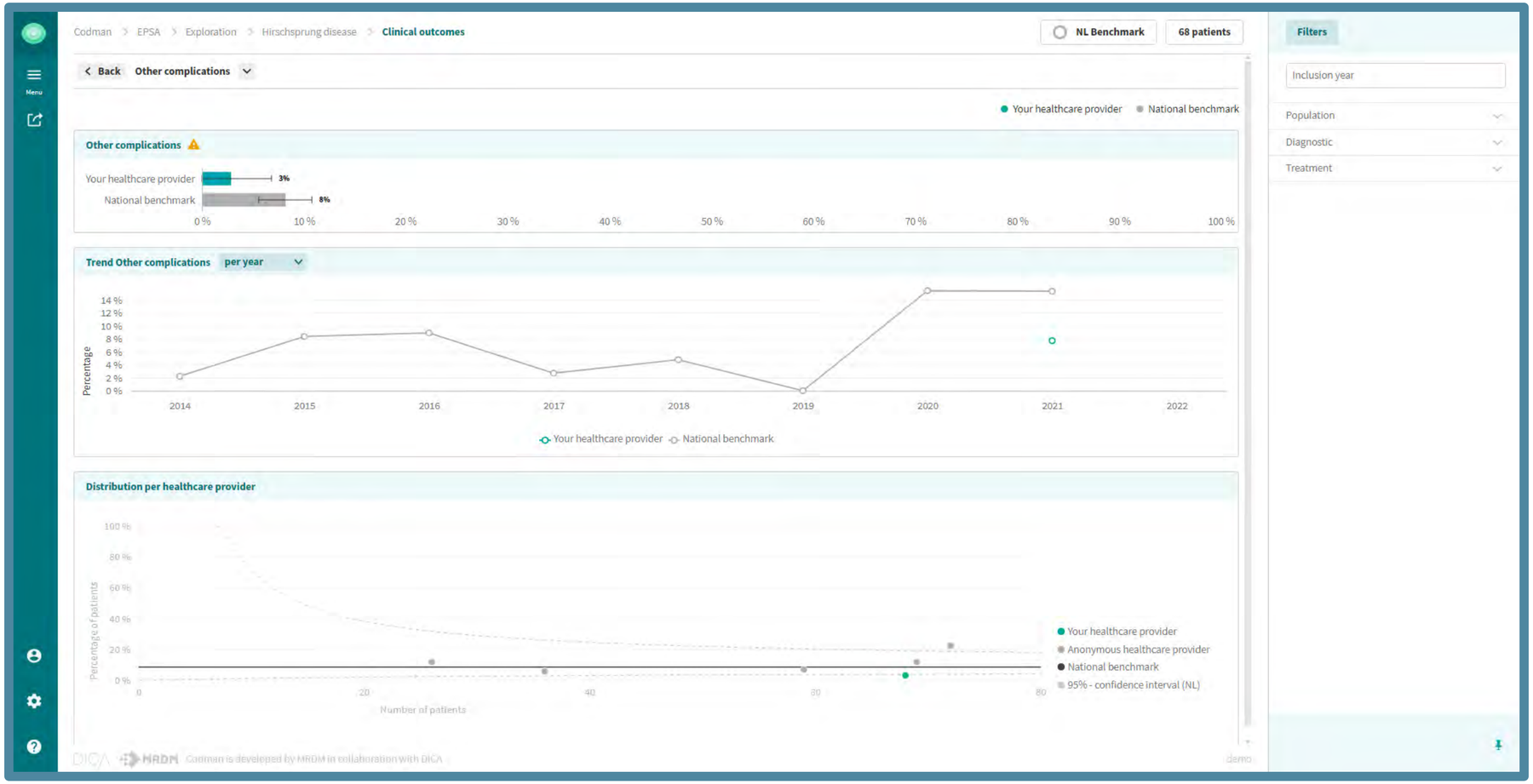
# EPSA|ERNICA Registry

## From burden to blessing: Codman Dashboard (DICA/MRDM)

# EPSA|ERNICA Registry

From burden to blessing: Codman Dashboard (DICA/MRDM)



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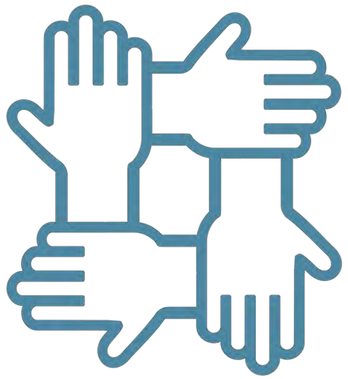
From burden to blessing: Annual Feedback Session



- Stimulating, supportive environment
- Discuss variation
- Learn from each other

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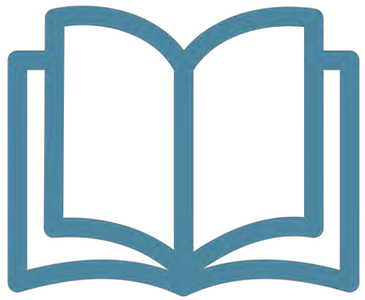
From burden to blessing: Research opportunities



- Improve knowledge of rare diseases
- Thorough application procedure
- Recognition of contributing centers

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Questions?

Contact: n.teunissen@dica.nl