

EPSA European Pediatric Surgical Audit



European
Reference
Network

for rare or low prevalence
complex diseases

 **Network**
Inherited and Congenital
Anomalies (ERNICA)

Registertage – April 2022



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Agenda

EPSA | ERNICA Registry – Registertage 2022

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

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Context



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

→ **registries**

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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!

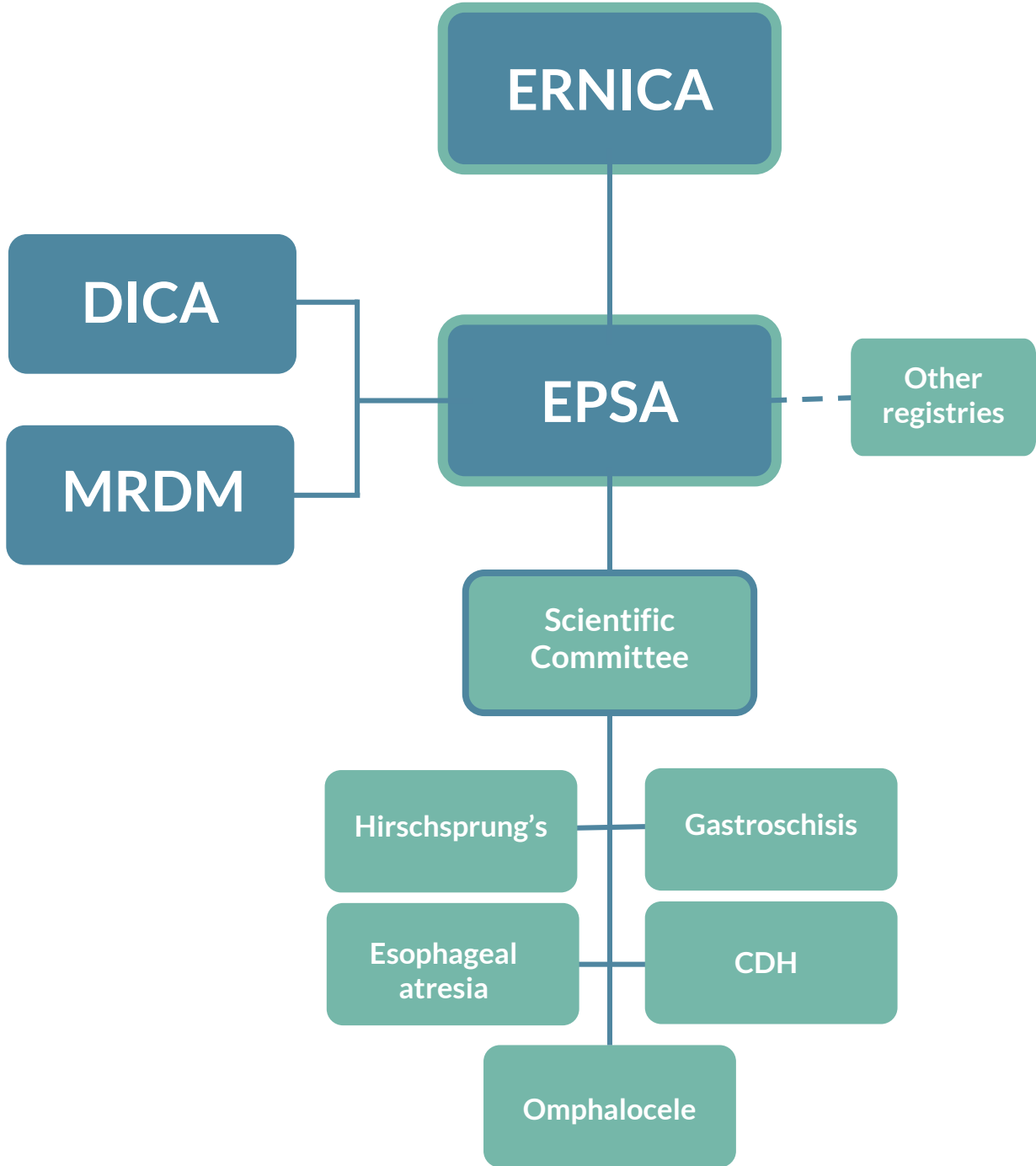
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What do we register - conditions



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

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Dutch Institute for Clinical Auditing



By clinicians
for clinicians

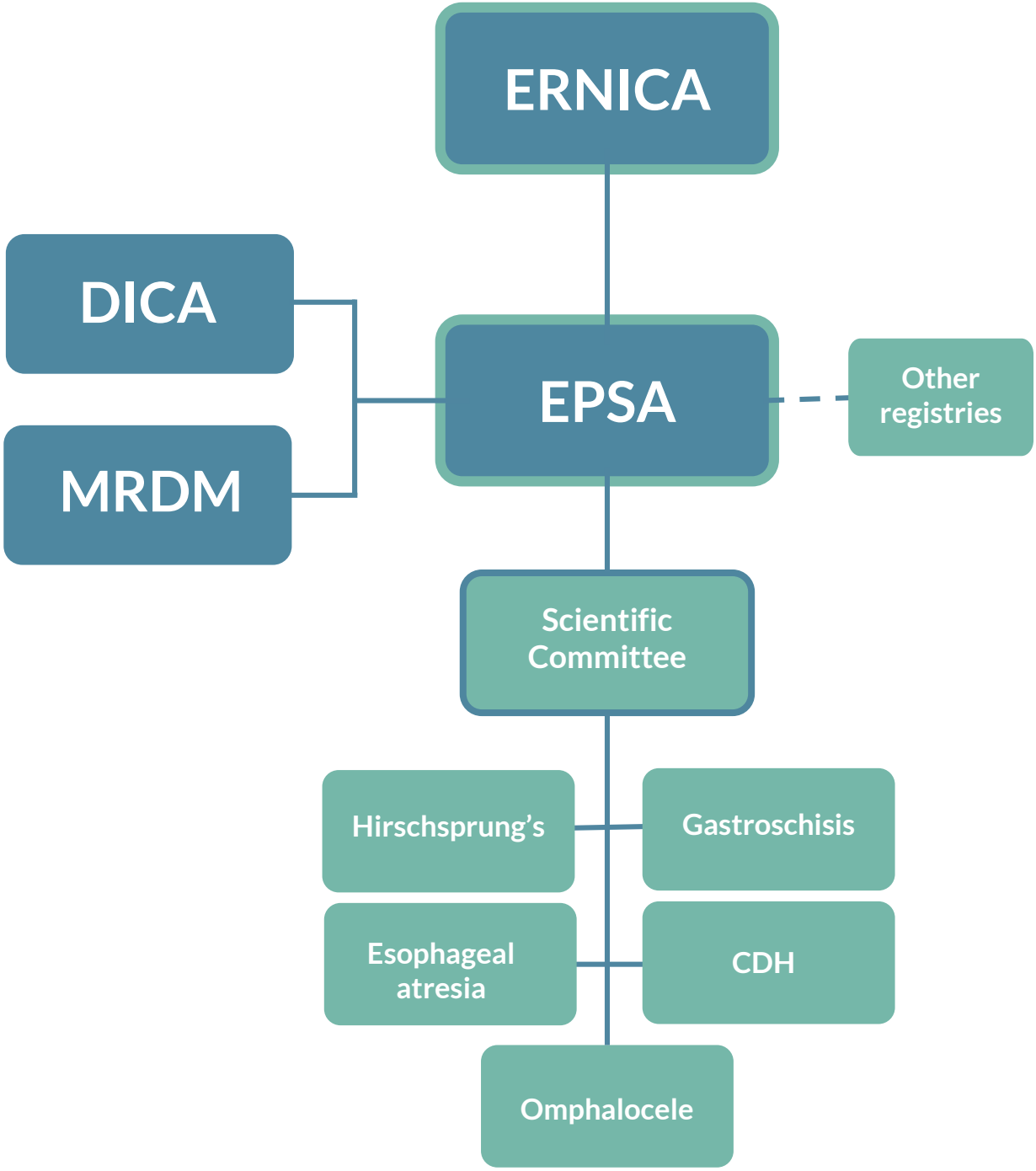


Provide
direct insight



Supporting
team

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The registration process



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How do we register – Survey (MRDM)

The screenshot displays the registration process for a patient with Malformation Congenital Diaphragmatic Hernia (ORPHA:2140) on 02-03-2022. The interface is divided into several sections:

- Navigation:** Survey > epsa-2022 > All patients > Patient the Netherlands/1354364745 > Malformation Congenital Diaphragmatic Hernia (ORPHA:2140)/02-03-2022
- Left Panel:** A sidebar menu with options: Patient overview, Patient Diaphragmatic Hernia 01-03-2022, Malformation Congenital Diaphragmatic Her..., Type of malformation, Diagnosis, Additional anomalies, Ventilation, ECMO, Surgery, Complications, and Discharge.
- Central Panel:** A list of categories for data entry: Type of malformation, Diagnosis, Additional anomalies, Ventilation, ECMO, Surgery, Complications, and Discharge (highlighted).
- Discharge Section:**
 - Transfer from ECMO centre ***: Radio buttons for No, Yes (selected), and Unknown.
 - Date of discharge ***: Text input field containing 14-04-2022.
 - Discharge to**: Radio buttons for Pediatric surgical center, Periferal hospital, Home (selected), and Other.
 - Weight at time of discharge (grams) ***: Text input field containing 2900.
 - At time of discharge**:
 - Additional oxygen**: Radio buttons for No (selected), Yes, and Unknown.
 - Tube feeding**: Radio buttons for No, Yes (selected), and Unknown.
 - Antireflux medication**: Radio buttons for No (selected), Yes, and Unknown.

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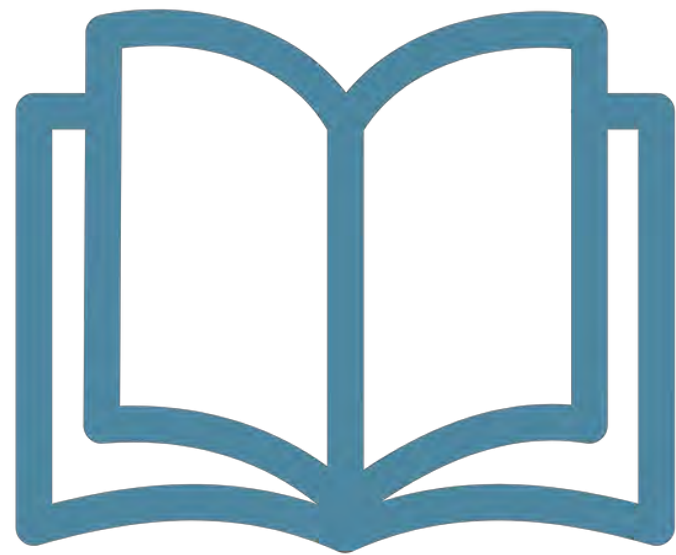
What do we register: data points

1.	Number of patients operated on, separated 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 aganglionic 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 gastroschisis 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



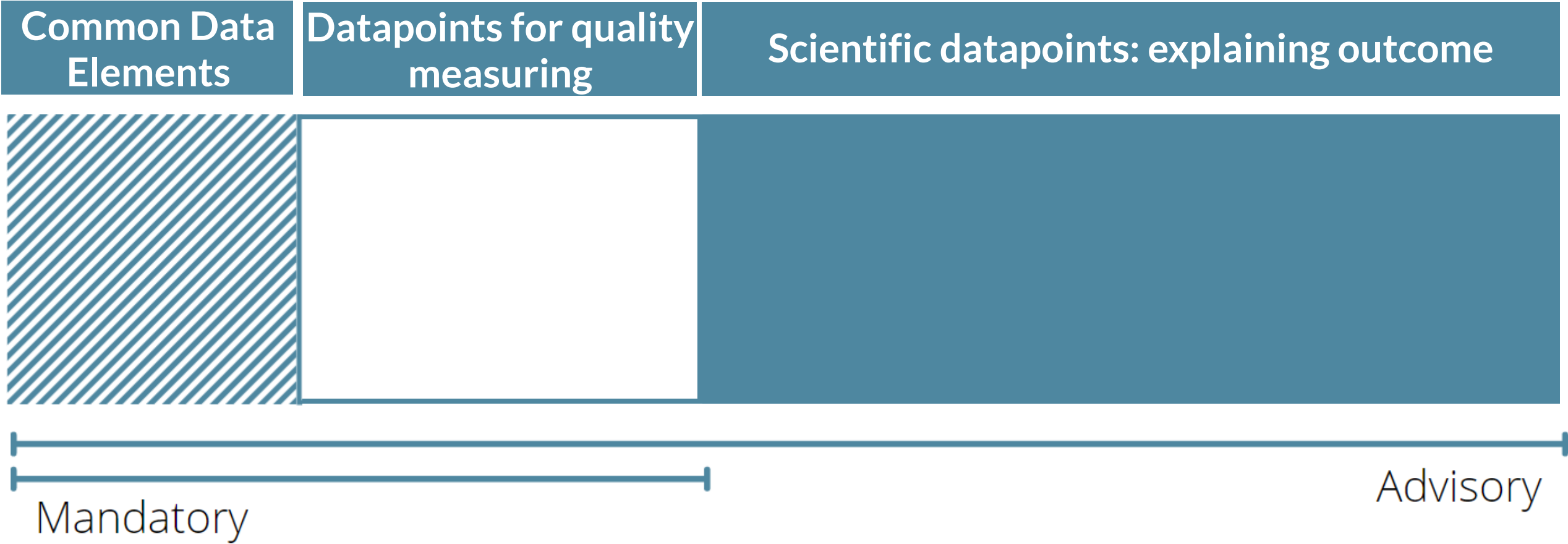
Using a Delphi
method to create
consensus



Patient involvement
through parallel
Delphi

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What do we register: structure dataset





EPISA European Pediatric Surgical Audit

Who participate?



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Purpose



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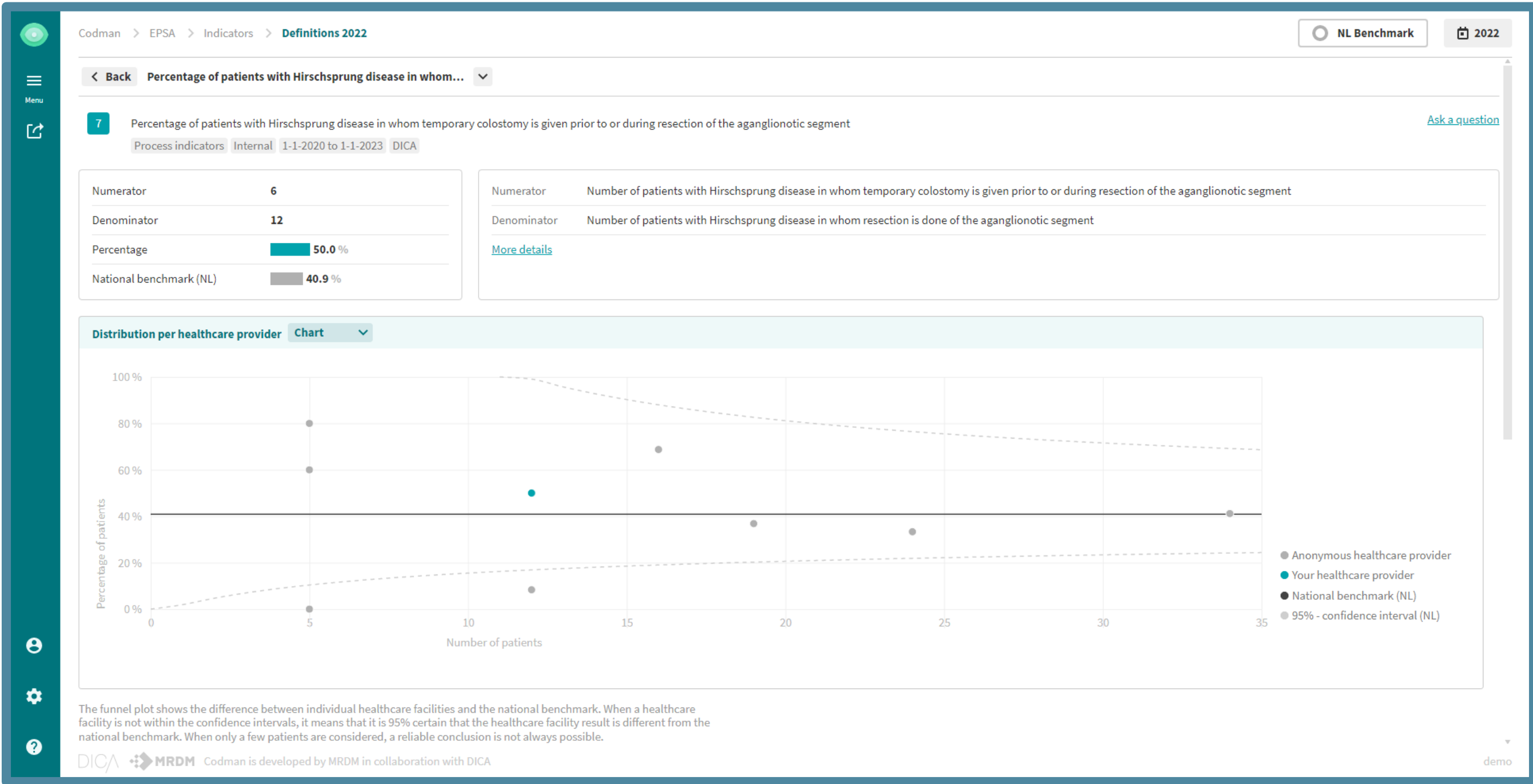
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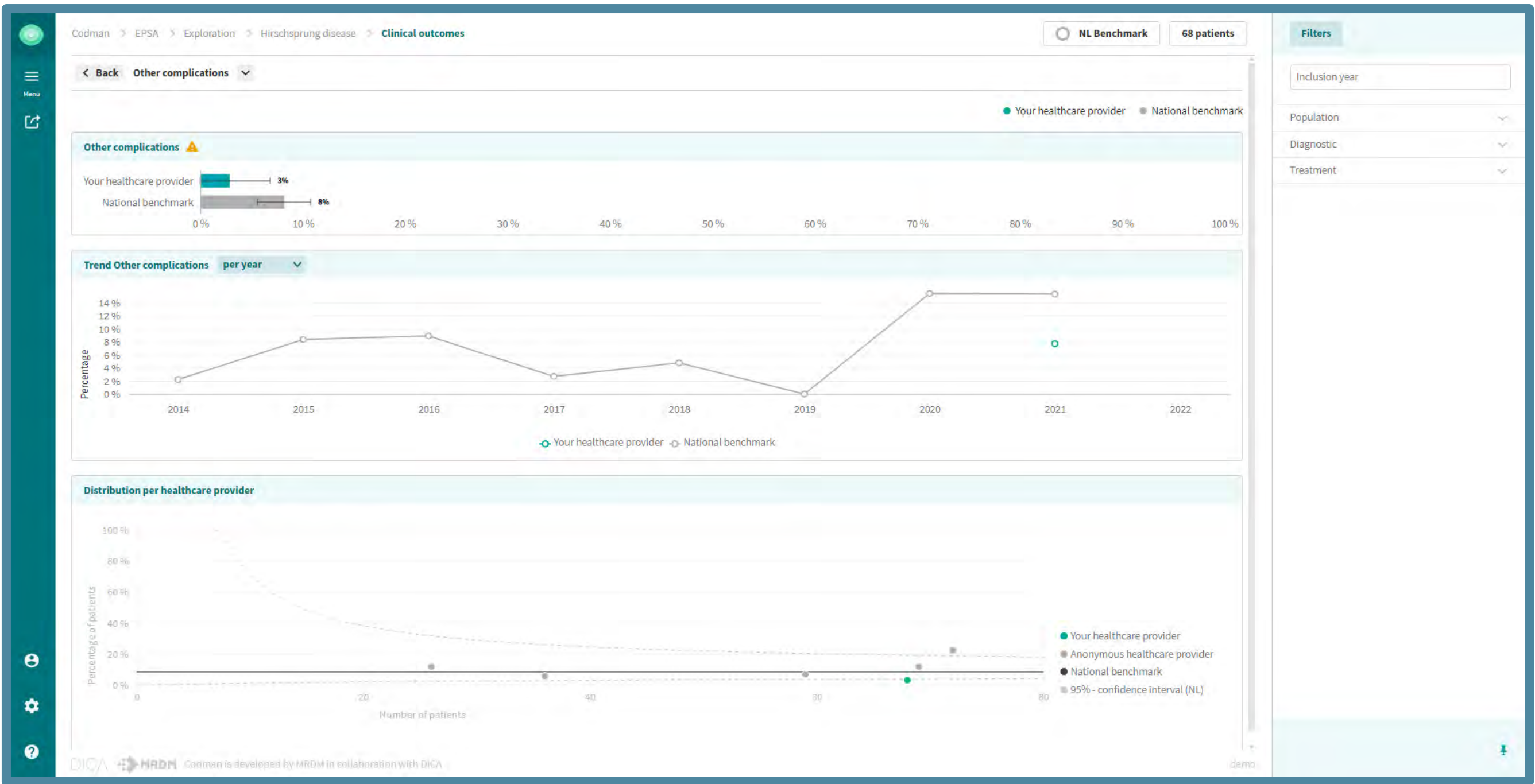
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From burden to blessing: Codman Dashboard (DICA/MRDM)



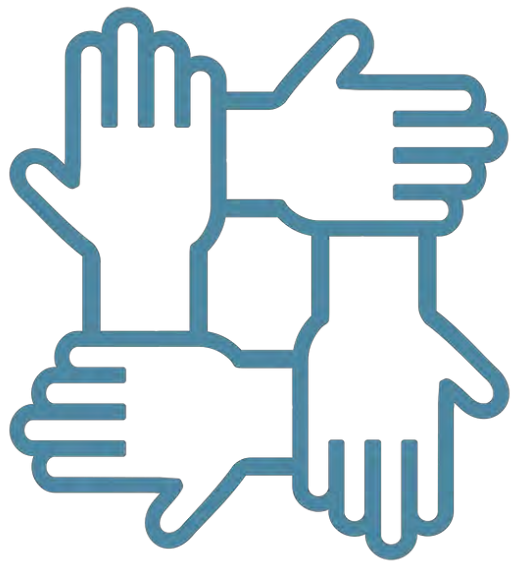
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From burden to blessing: Codman Dashboard (DICA/MRDM)



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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?



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