

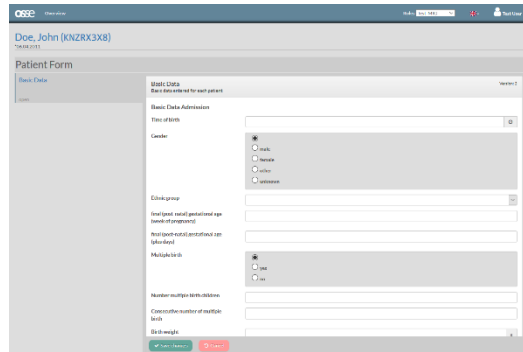
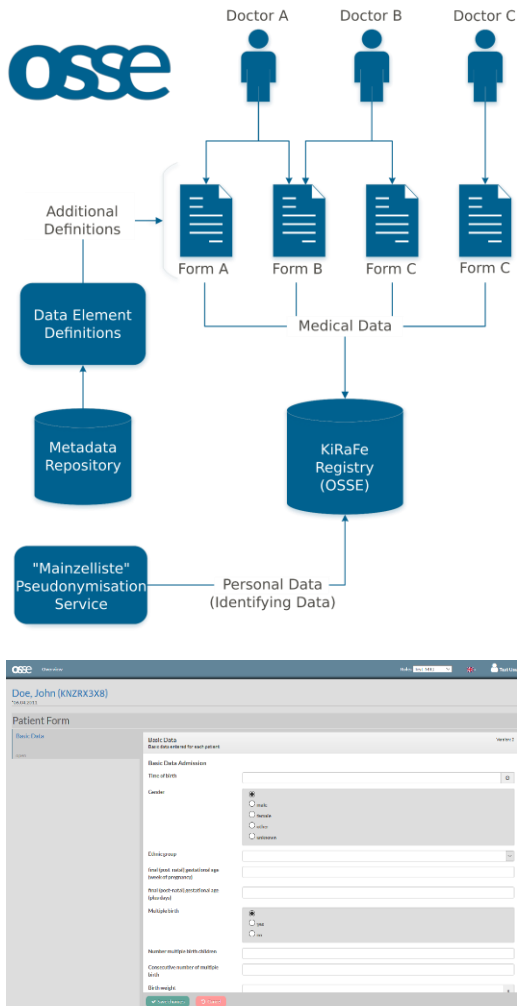
Establishing a Registry on Rare Congenital Malformations in Germany

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Neonatal surgical care is not centralized in Germany. In 2015, 89 departments of Paediatric Surgery treated i.e. 93% of the abdominal wall defects (average less than 5 cases/unit). There is no existing national registry on rare congenital malformations in Germany. Therefore, the importance of quality measurements for the care of rare congenital malformations is obvious.

Open Source Registry System for Rare Diseases in the EU



- 2014**
 - Decision: Registry on rare congenital malformations: (esophageal atresia, intestinal atresia, abdominal wall defects, diaphragmatic hernia + NEC/FIP)
- 2015**
 - General data collection on neonatal surgery of 2013/14
- 2016**
 - General Organization
 - DGKCH-Group work: parameters
- 2017**
 - Project lead: Paed. Surg., Frankfurt
 - Project partner: MIG Frankfurt, KEKS e.V.
 - Funding application with GBA not successful
- 2018**
 - DGKCH-Expert-group on parameters (DELPHI): above + M. Hirschsprung
- 2019**
 - Funding successful
 - Workshop on parameters: above + MMC + anorectal malformations
 - Software: OSSE
- 2020**
 - Ethic approval
 - Server, Software, Registration at ERDRI.dor

Participation 2020: 83 German Hospitals, 3 non-German Hospitals

The registry will allow the measurement of quality attributes of rare congenital malformations. It will facilitate recruitment of patients to clinical trials and serve as a basis for policy making and planning of health and social services for people with rare disorders.

The registry is set up in modules for different malformations which will allow expansion in the future.

The inclusion of all Paediatric Surgeons though the German Society of Paediatric Surgery, adjacent disciplines and patient support groups increase the acceptance and participation in the ongoing work.



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