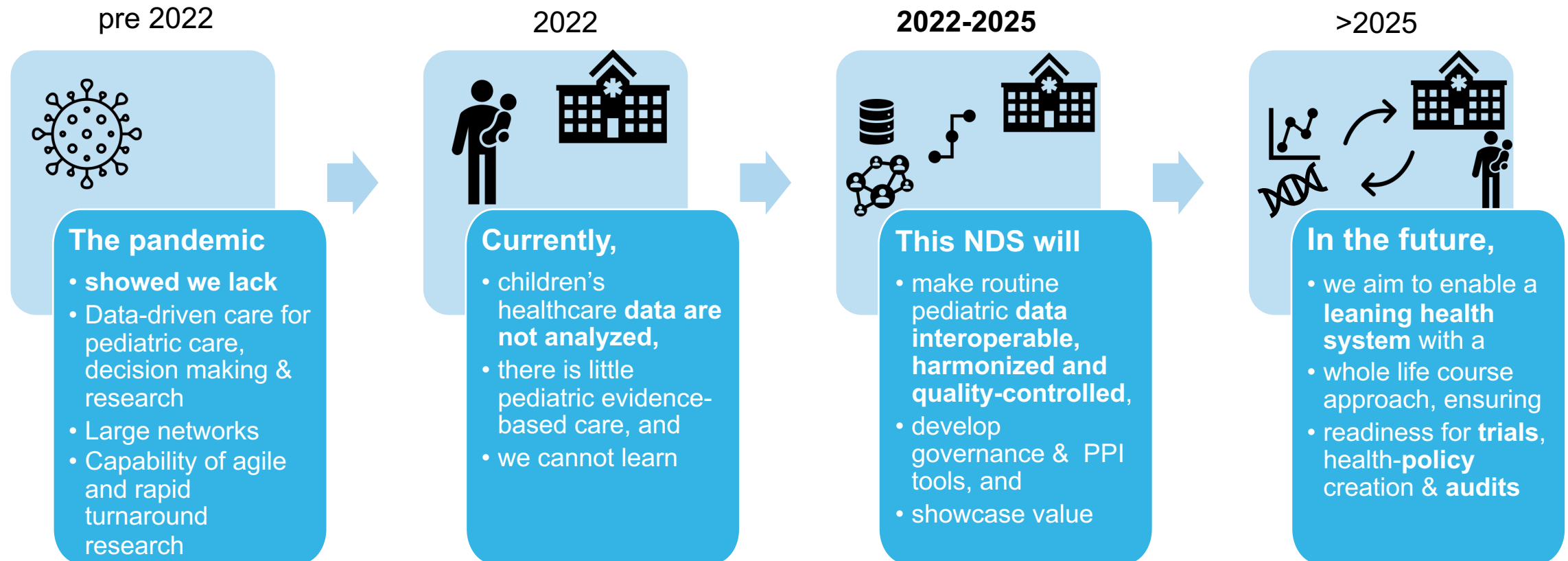


# Pediatric Personalized Research Network Switzerland (SwissPedHealth) – a Joint Pediatric National Data Stream

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Prof. Dr. med. Luregn Schlapbach (University Children's Hospital Zurich)  
Prof. Dr. Julia Vogt (ETH Zürich)  
on behalf of the SwissPedHealth consortium

# SwissPedHealth is designed to address the needs of children

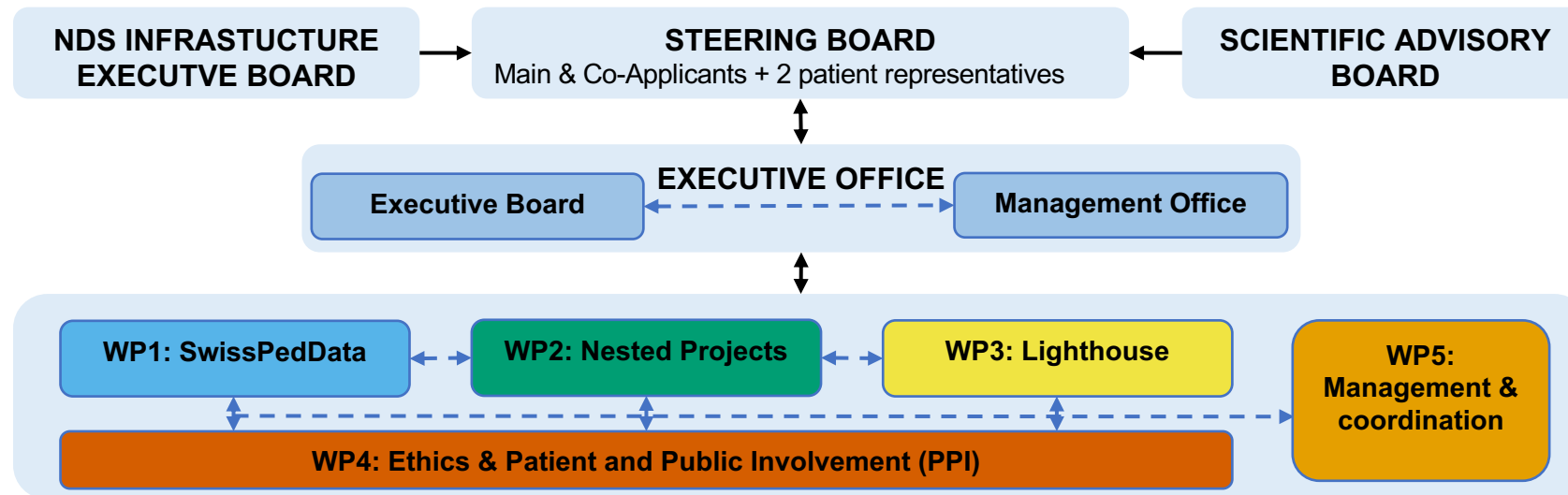


# Governance: a joint effort towards the greater good

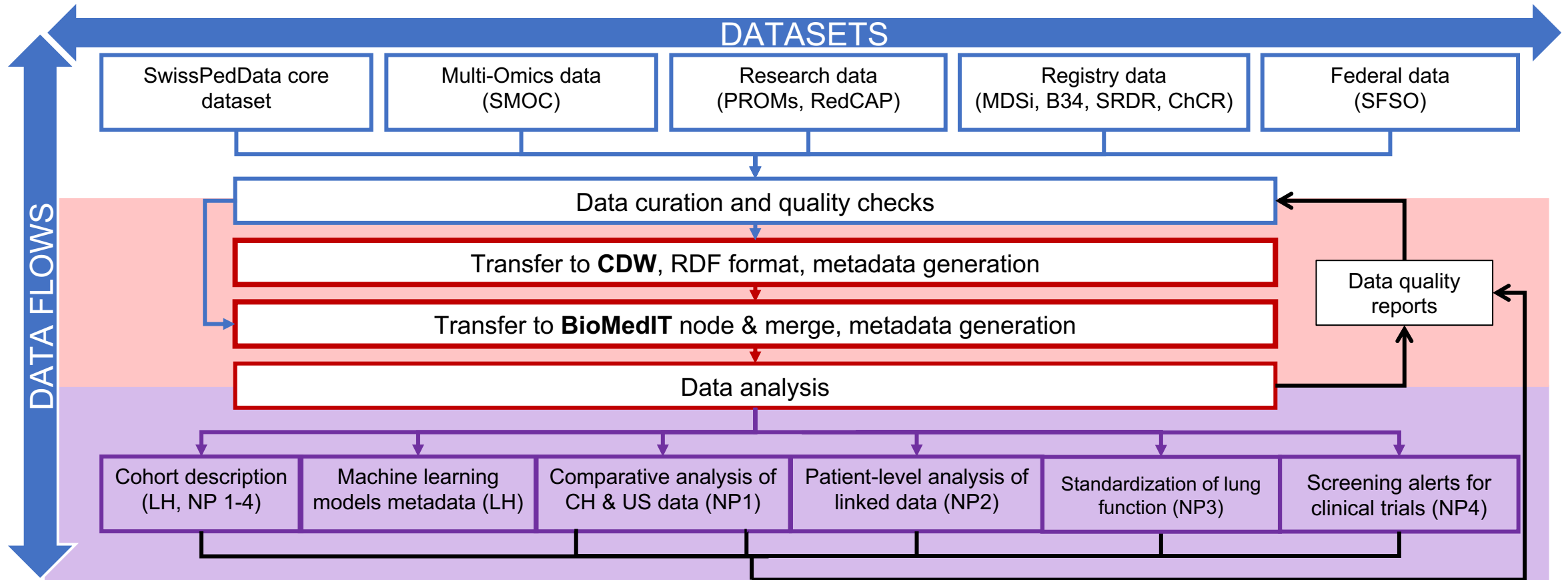
We build on umbrella Infrastructure Consortium Agreements and ethics for the data stream.

Our consortium:

- unites experts from all 5 university children's hospitals and 2 A-level hospitals
- bridges ETH domain with pediatric institutions in Switzerland with a focus on rare diseases
- is diverse in terms of hospital, gender, age, discipline, research focus



# Data flow and data management



# Nested Projects: Using SwissPedData to study key pediatric problems

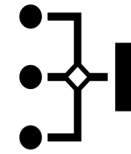
## Obesity

- Assessing prevalence, growth patterns, risk factors, comparing Swiss vs US data



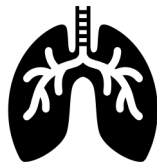
## Cancer

- Improving data flows to and from the Swiss Childhood Cancer Registry



## Chronic respiratory disease

- Standardizing data extraction of pediatric lung function tests



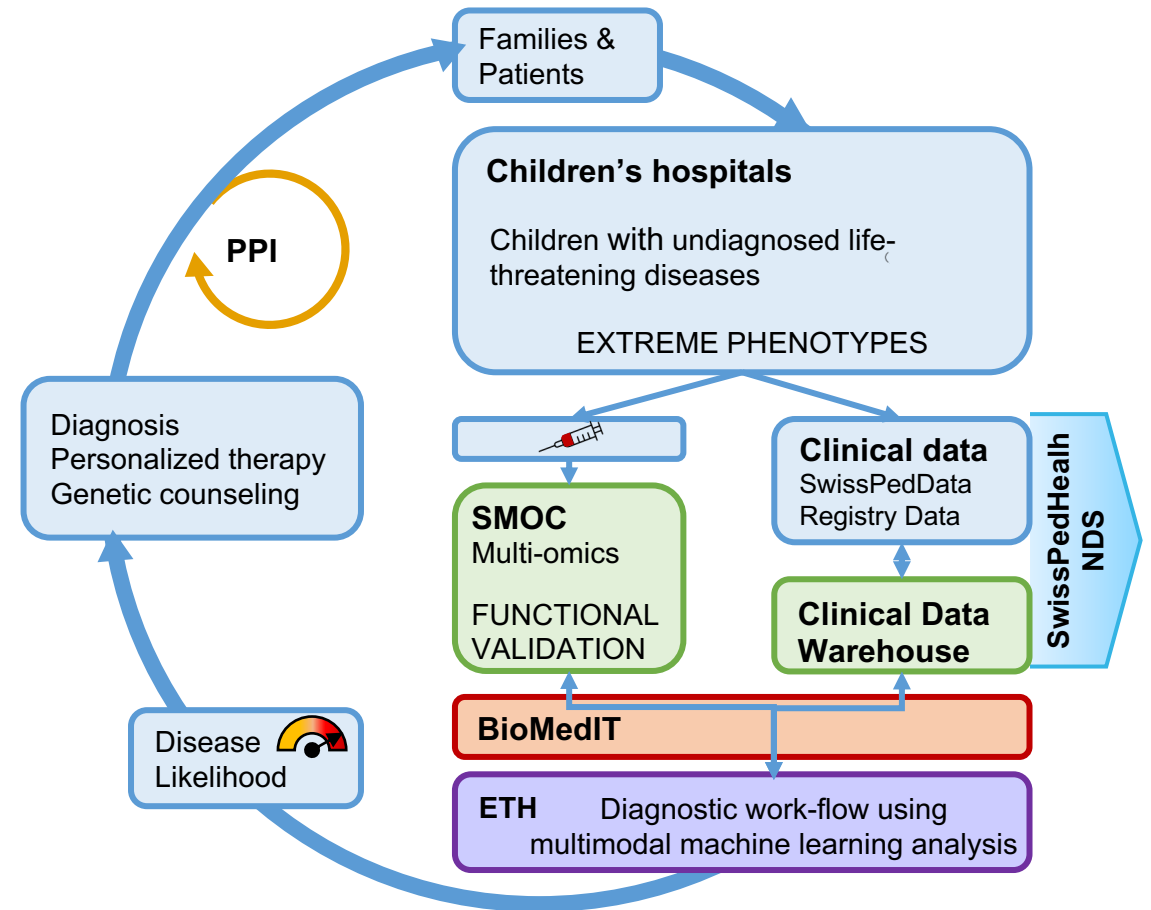
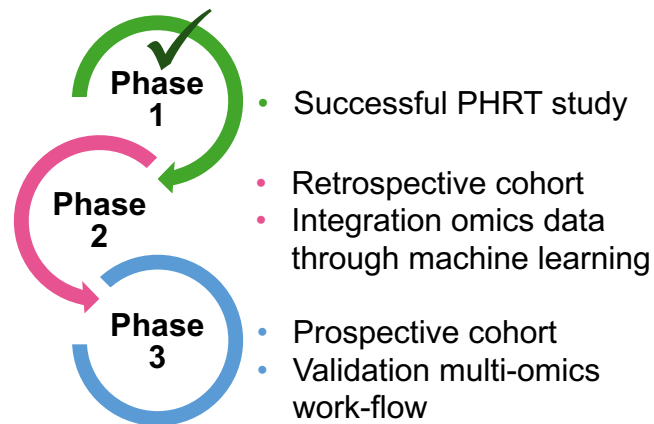
## Infectious diseases

- Investigating antibiotic utilization patterns

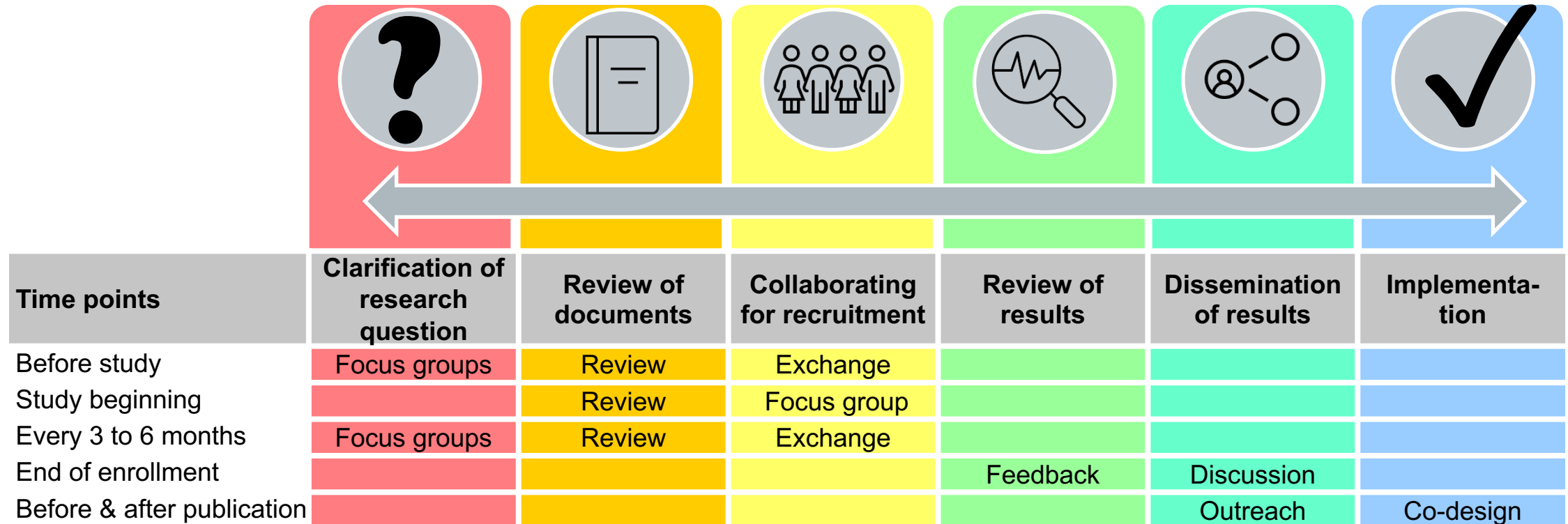


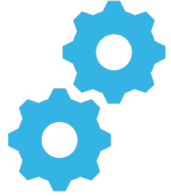
# Lighthouse: A multi-omics work-flow to diagnose rare diseases in children with extreme phenotypes

- Pediatrics to a large extent has become a discipline of rare diseases
- Rapid WES / WGS programs:
  - have >50% undiagnosed patients
  - are not optimized for discovery
- Multi-omics can improve diagnostic yield and provide functional validation



# Patient & Public Involvement strategy





## Challenges

- Limited pediatric experience in CDWs
- Registries with different governance
- Pediatric data siloes (by institution, by discipline)
- Validity of extracted data – need for data quality checks
- Address needs of patients and the public



## Opportunities

- Shape a data-driven, agile, learning health care system
- Boost personalized care and evidence-based medicine to children and their families
- Work together with patients, families, the public
- Foster pediatric research networks
- Provide data for research, future trials & surveillance



# The SwissPedHealth consortium

Expertise in pediatrics, rare diseases and omics, epidemiology, governance, PPI, computer science and engineering to improve children's health care.

## Main applicants

- Schlapbach, Luregn
- Vogt, Julia

## SPHN co-applicants

- Kuehni, Claudia
- Bielicki, Julia
- Posfay-Barbe, Klara

- Baumgartner, Matthias
- Latzin, Philipp
- Giannoni, Eric

## PHRT co-applicants

- Fellay, Jacques
- Borgwardt, Karsten
- Vayena, Effy

## Associated applicants

- Ormond, Kelly
- Stocker, Martin
- Lauener Roger
- Schulzke, Sven

- Froese, Sean
- Goetze, Sandra
- Pedrioli, Patrick
- Pachlopnik Schmid, Jana

- Zamboni, Nicola
- Rauch, Anita
- Spycher, Ben
- Forrest, Christopher