

# European paediatric research landscape

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# Policy landscape

- National
  - Project funding
  - Infrastructure
- European
  - Strategic and coherent planning
  - ESFRI
  - Funding for initiation of Research Infrastructures (but not maintenance)
- International
  - Strategic and coherent planning
  - OECD

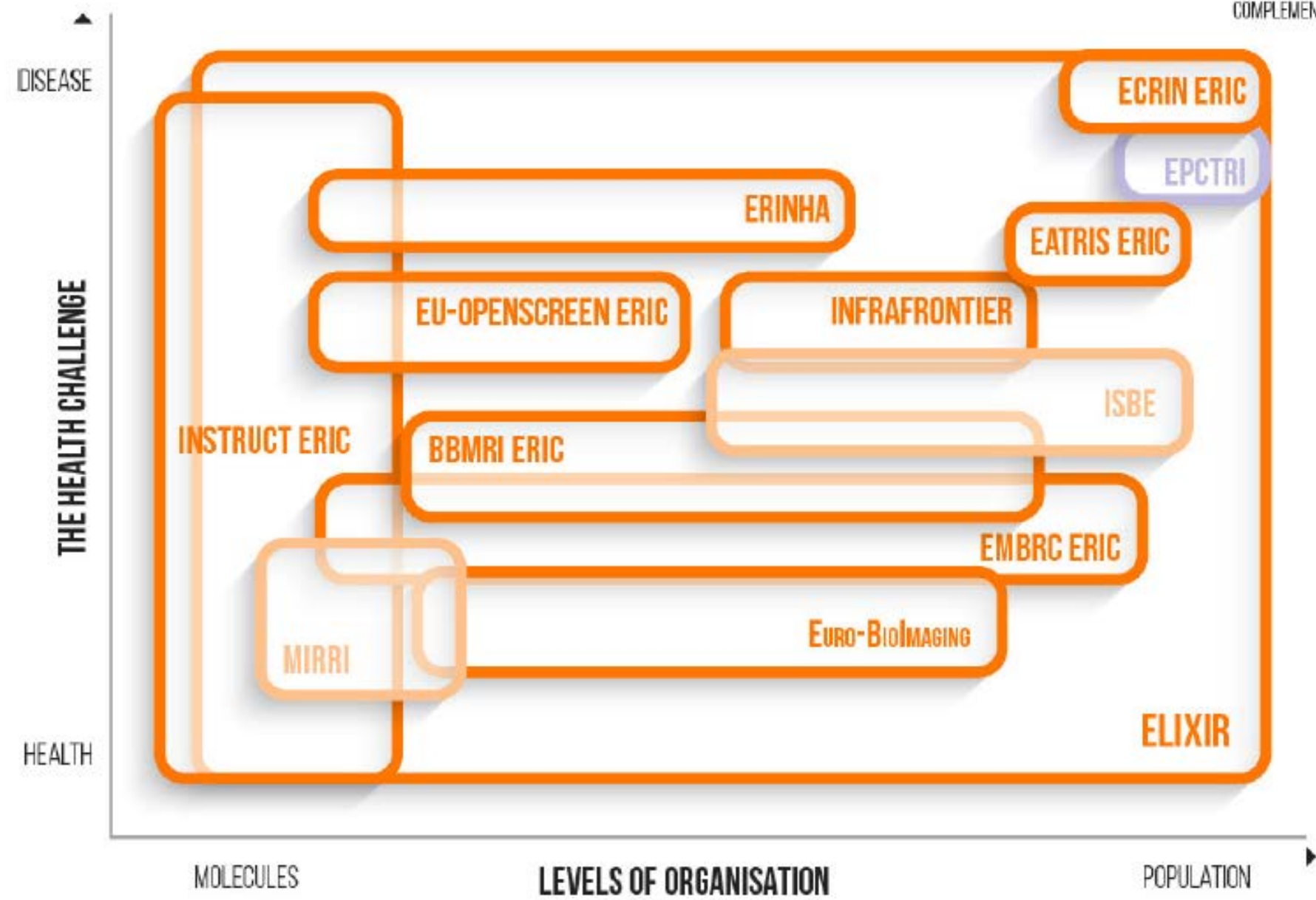
ESFRI LANDMARK



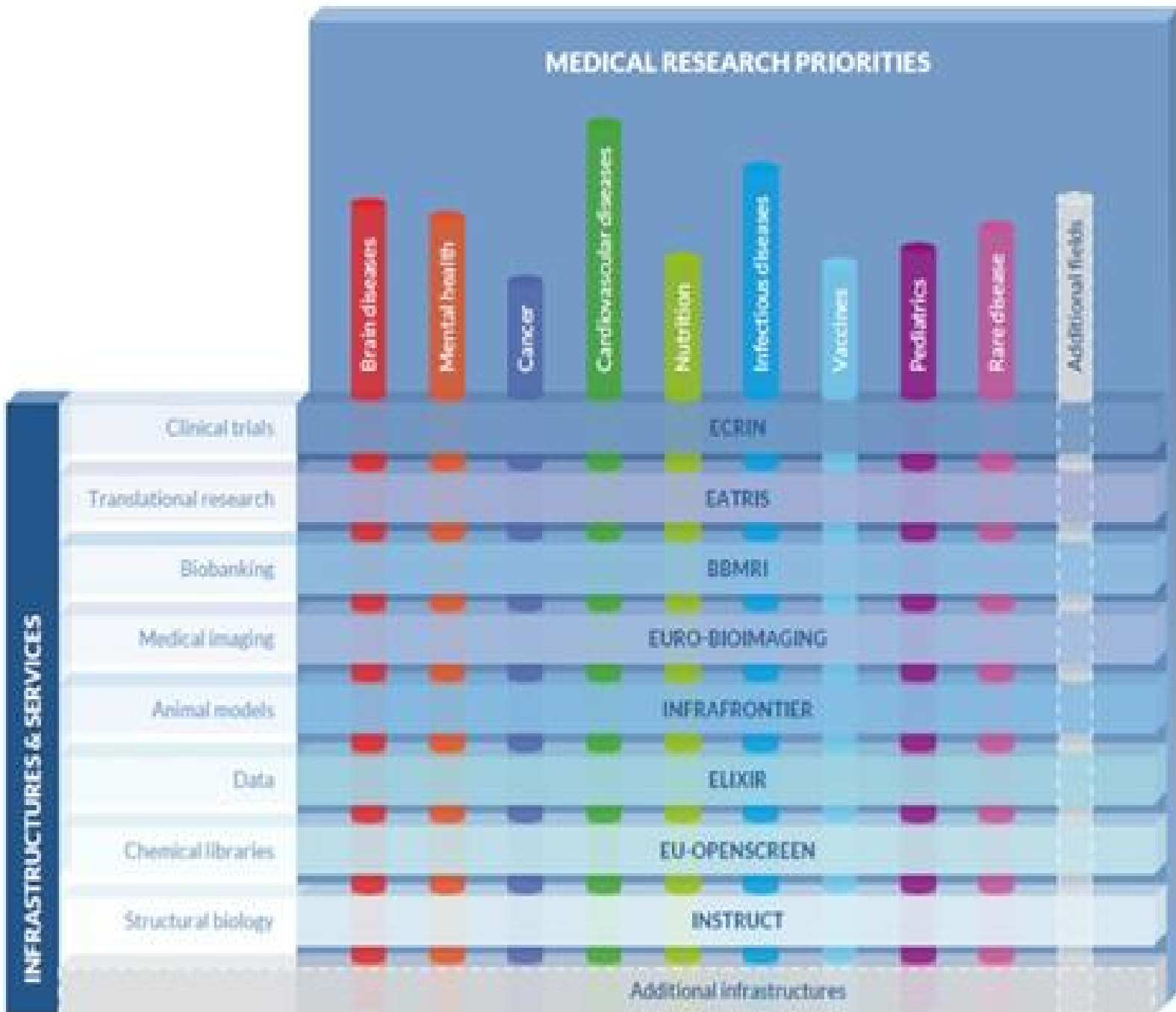
ESFRI PROJECT



COMPLEMENTARY PROJECT



# MEDICAL RESEARCH PRIORITIES



A distributed RI consists of a Central Hub and interlinked National Nodes.

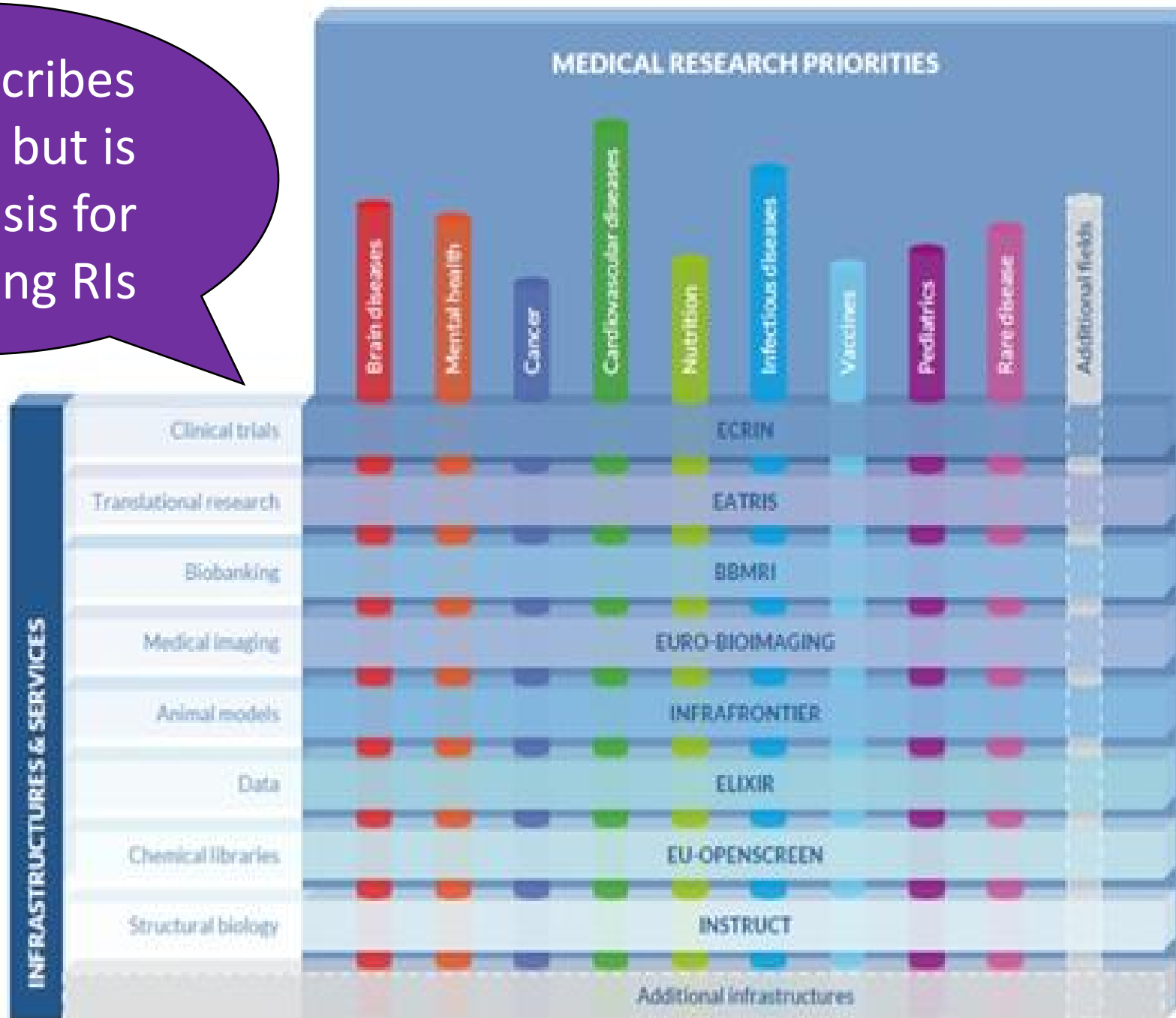
A distributed RI particularly needs to:

- i) Have a unique specific name, legal status, a governance structure with clear responsibilities and reporting lines, including international supervisory and relevant external advisory bodies
- ii) have legally binding attributions of coordination competences and resources to the Central Hub
- iii) have a unique access policy and provide for a single point of access for all users with a support structure dedicated to optimise the access for the proposed research;
- iv) have a user programme absorbing a relevant fraction of the total capacity of the RI;
- v) identify and adopt measurable Key Performance Indicators addressing both excellence of scientific services and sustainability;
- vi) have a human resources policy adequate to guarantee the effective operation of the Central Hub supporting the research, users programme, education and training by equal opportunity hiring and secondments;
- vii) define a joint investment strategy aimed at strengthening the RI through the Nodes and the common/shared facilities.

These features mark the difference of a RI with respect to a coordinated research network (international collaborations of fully independent research performing organizations). Nodes may be absorbed partially by the distributed RI while maintaining their national or institutional programmes, but the capacity and amount of resources engaged in the RI must be coordinated and managed by the Central Hub according to agreed statutes and common rules and procedures of the legal RI consortium.

Services and clinical communities meet the definition of RIs

This describes services but is not a basis for identifying RIs

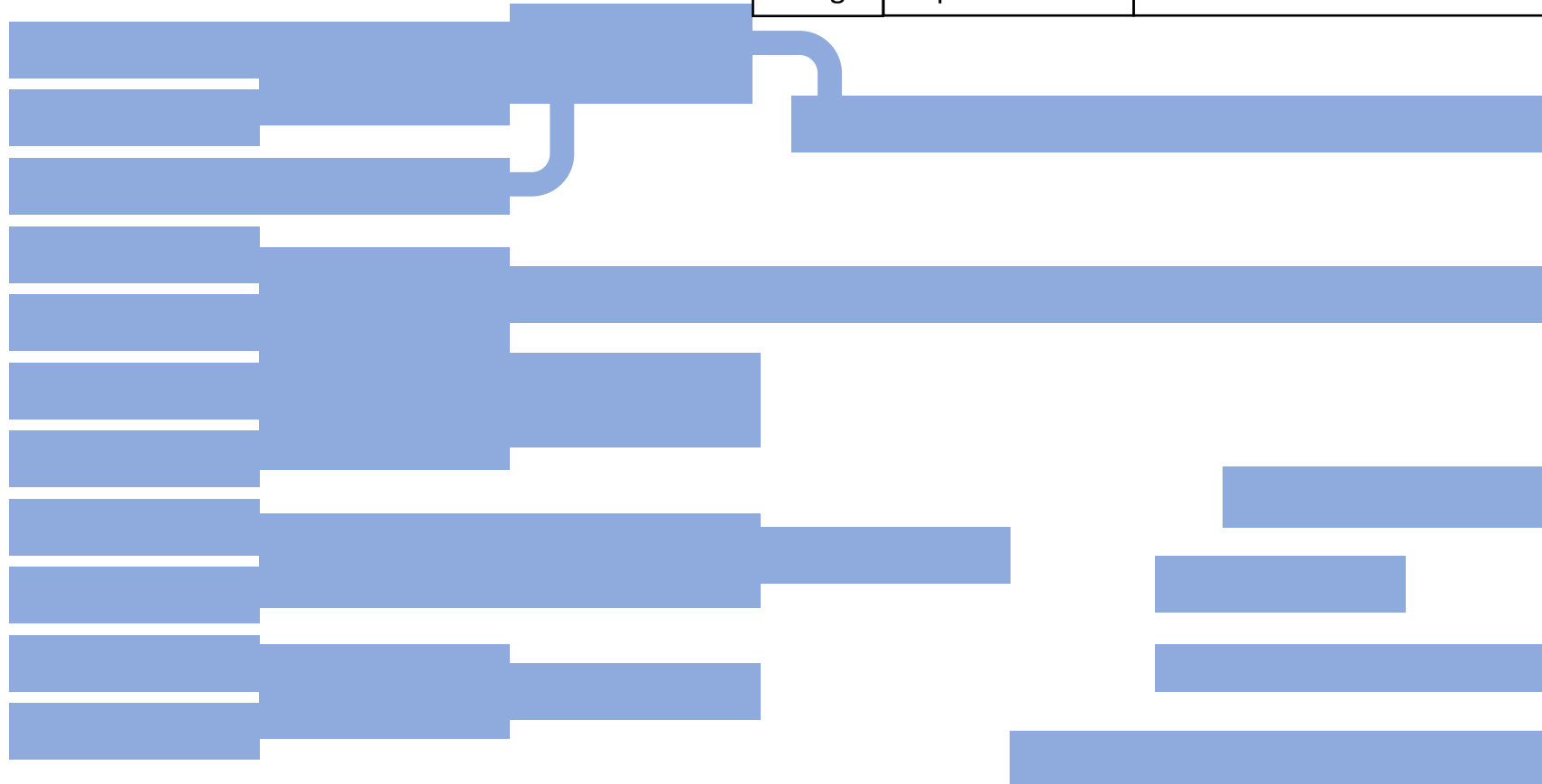


# Paediatric research specificities

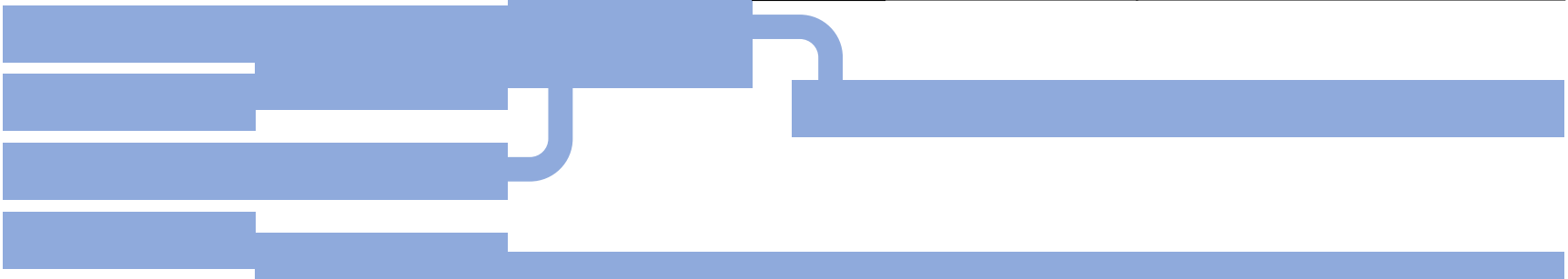
- Biology
- Conduct
- Ethics
- Regulation



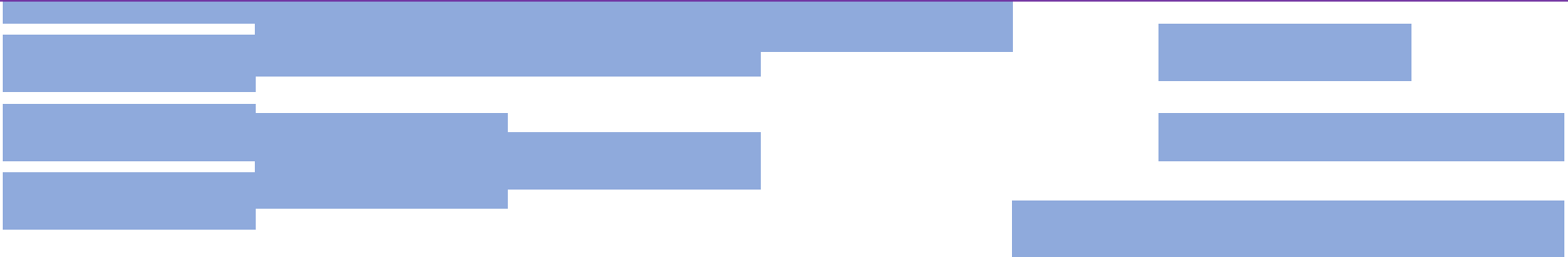
|              |   |             |          |                |                  |
|--------------|---|-------------|----------|----------------|------------------|
| Foundational | Candidate identification and optimisation | Preclinical | Clinical |                |                  |
|              |   |             | Design   | Implementation | Conduct at sites |



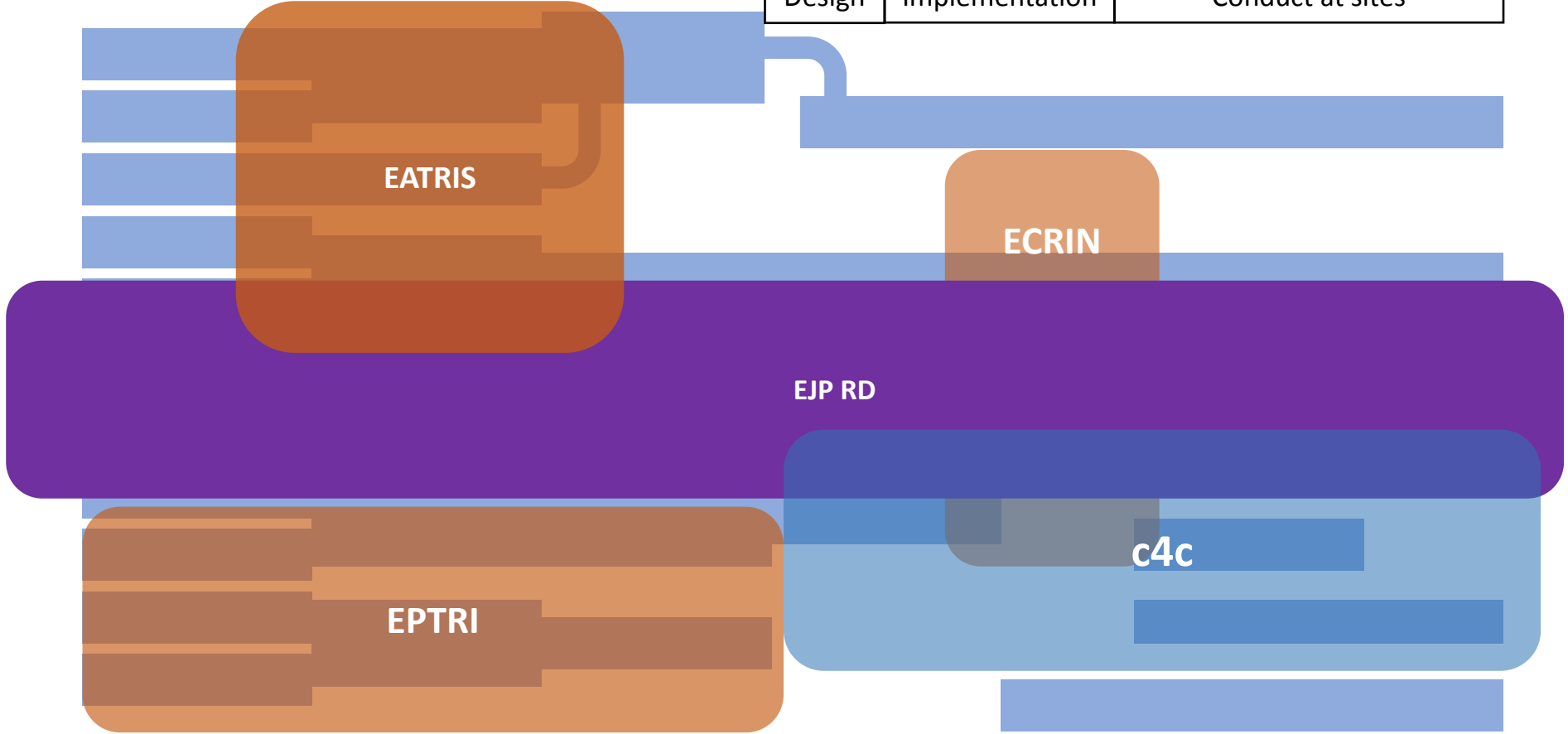
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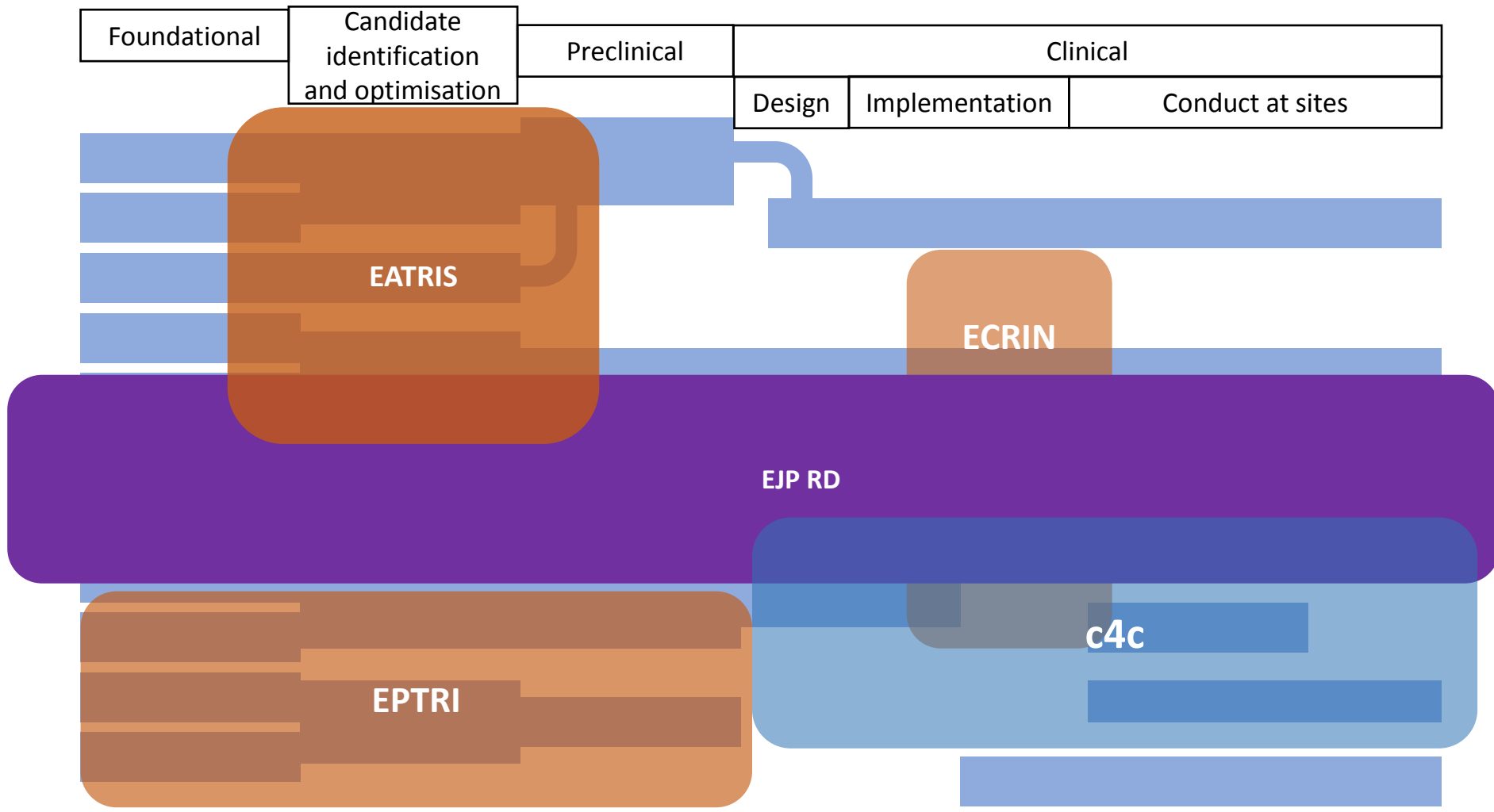


# EJP RD



|              |   |             |          |                |                  |
|--------------|---|-------------|----------|----------------|------------------|
| Foundational | Candidate identification and optimisation | Preclinical | Clinical |                |                  |
|              |   |             | Design   | Implementation | Conduct at sites |





Establish core business

Negotiate boundary issues

Sponsor

Investigators

Sites

Clinical experts

Children,  
Young  
People and  
Families

Methodological experts

EATRIS

BBMRI

Sponsor

Investigators

ERNs

Single Contact Point

ECRIN

Specialty networks

National Hubs

EJP-RD

Expert Advice  
•Strategic feasibility  
•Scientific/clinical  
•Do-ability

EPTRI

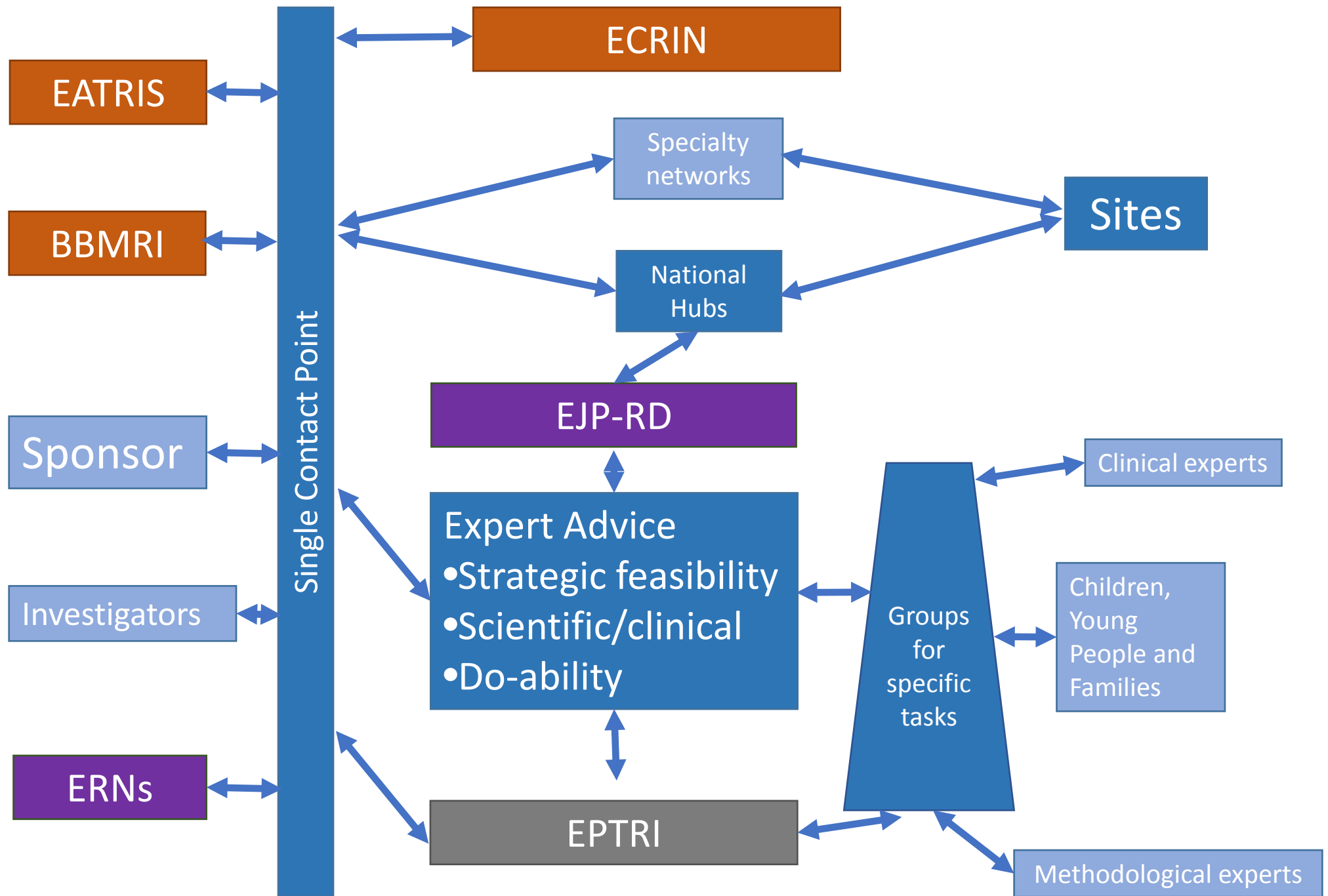
Groups for specific tasks

Sites

Clinical experts

Children, Young People and Families

Methodological experts









ECRIN

EATRIS





ERNS / EJP-RD

Paediatrics



Reusable infrastructure of expertise and sites  
that supports vertical growth and horizontal progress

Some growth has specific support and guidance



ERNs / EJP-RD

Paediatrics

