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EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE

The EPTRI project challenges

EPTRI Open Meeting – April 2-3, 2020

EPTRI background

THE PROBLEM: a serious lack of medicines for children

Existing therapies are currently used in lack of specific paediatric studies results, in an off-label manner, in a percentage variable from 30 to 80%, depending by children age and therapeutic category of the drug

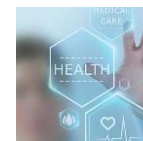This Project has received funding from the European Union's Horizon 2020 programme under Grant Agreement No. 777554

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EPTRI Community

Legend:
- MEMBER COUNTRIES
- NON-MEMBER COUNTRIES

29 partners from
21 EU/non EU countries
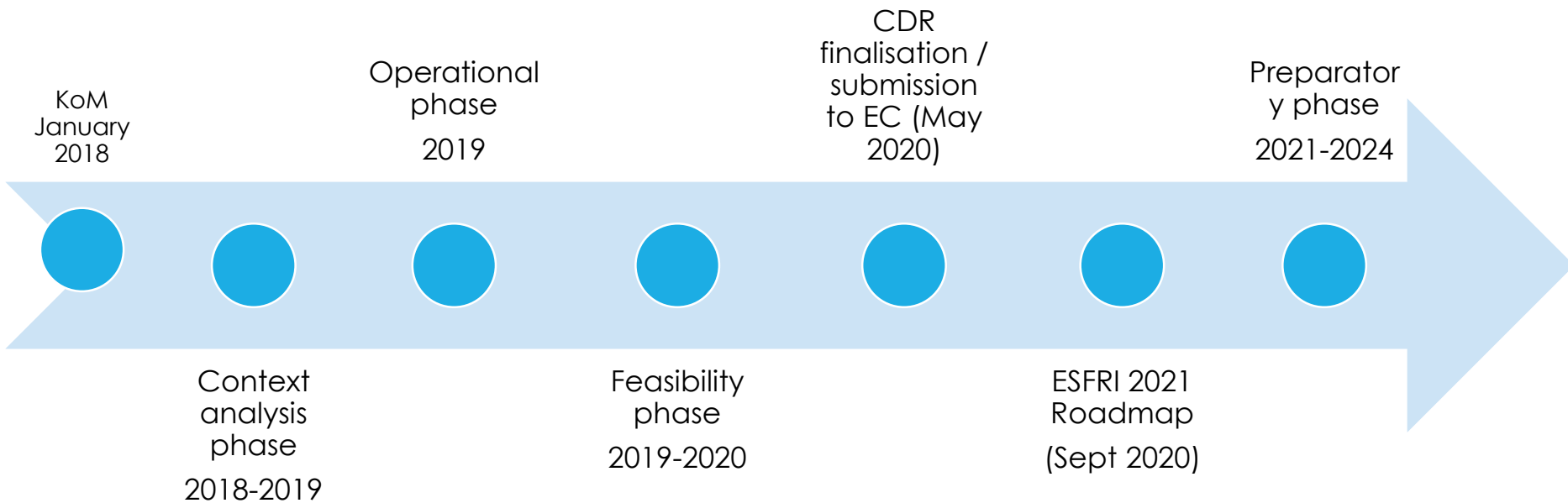
259 research units candidate
as EPTRI providers from
29 EU / non EU countries

337 potential users responding
to the survey

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EPTRI life cycle

KoM January 2018

Operational phase 2019

CDR finalisation / submission to EC (May 2020)

Preparatory phase 2021-2024

Context analysis phase 2018-2019

Feasibility phase 2019-2020

ESFRI 2021 Roadmap (Sept 2020)

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EPTRI Context Analysis phase
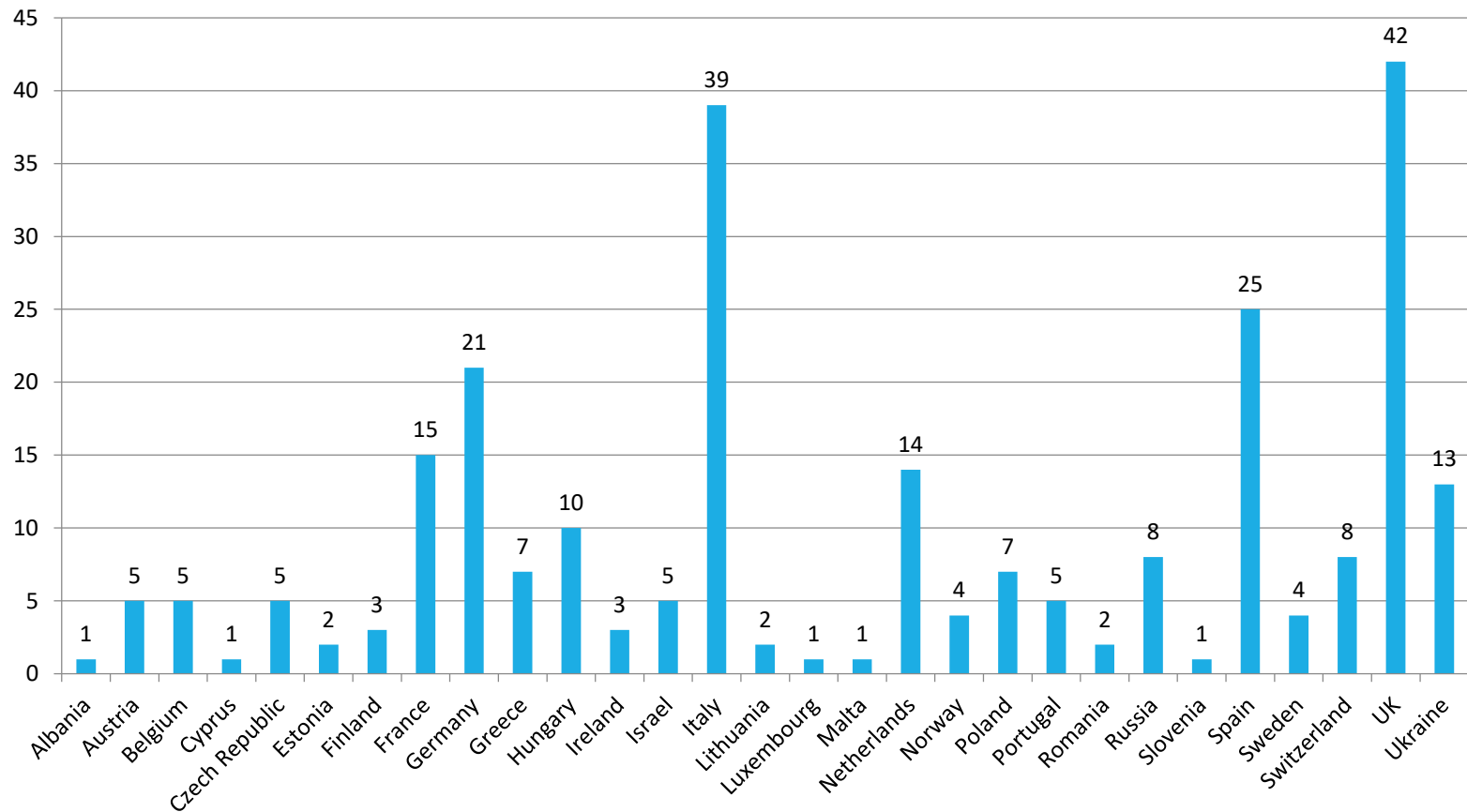
Users survey
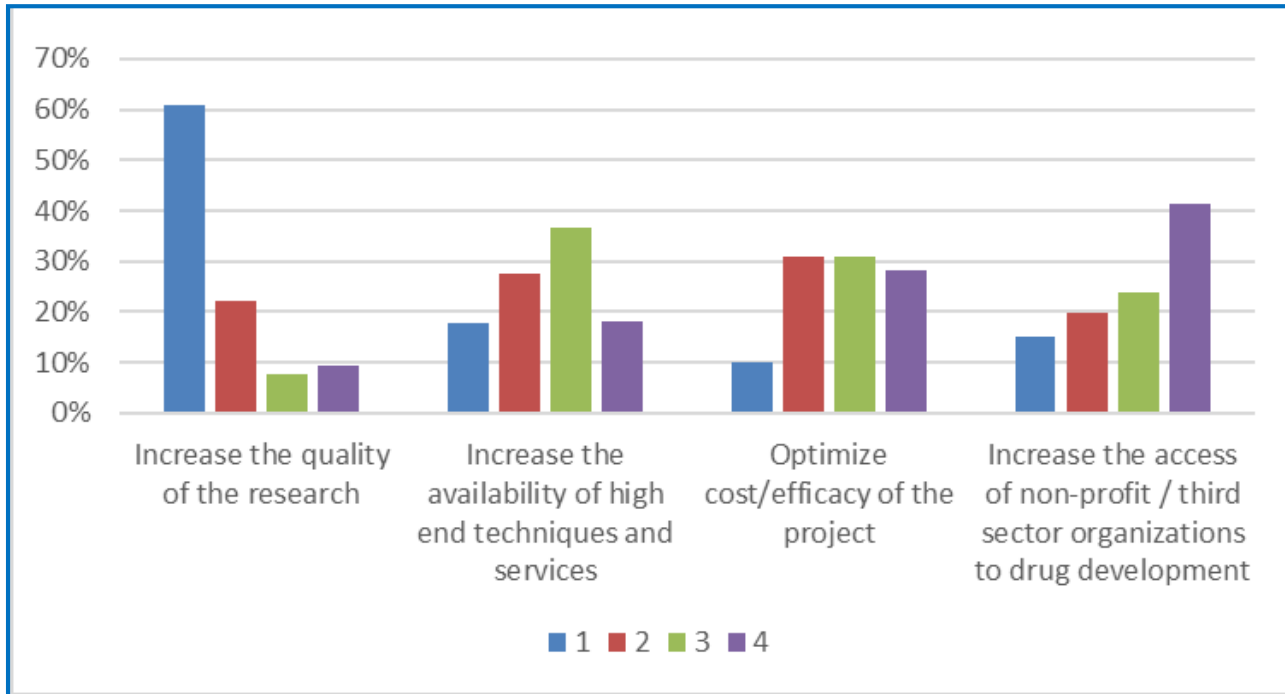
Why use EPTRI?

Operational phase

Research units mapping

Users survey

Gap Analysis

EPTRI Technical Design and the Conceptual Design Report (CDR)

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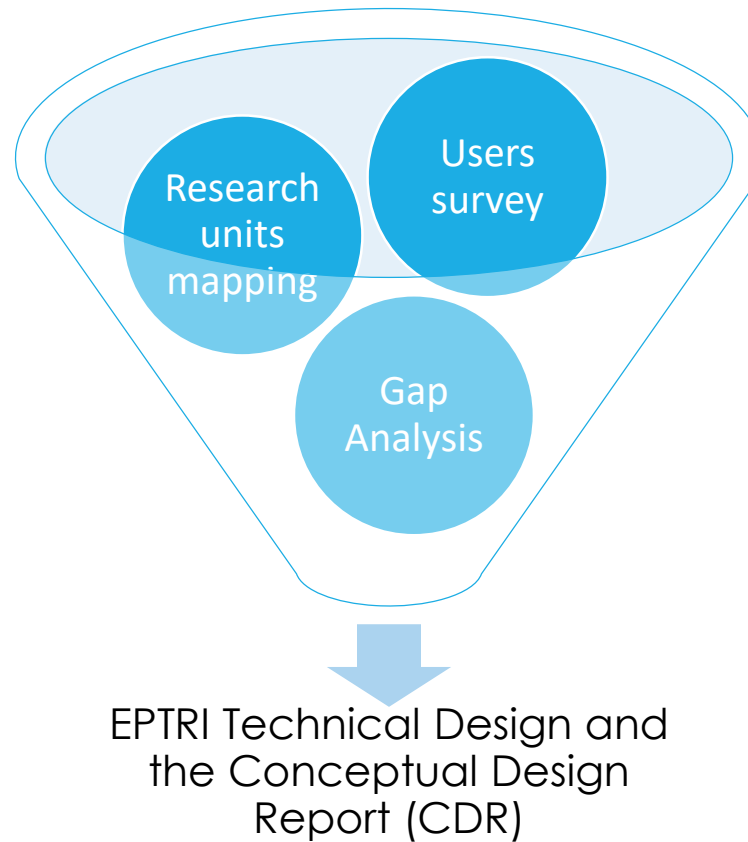
EPTRI Technical Design

Hub and Spoke model

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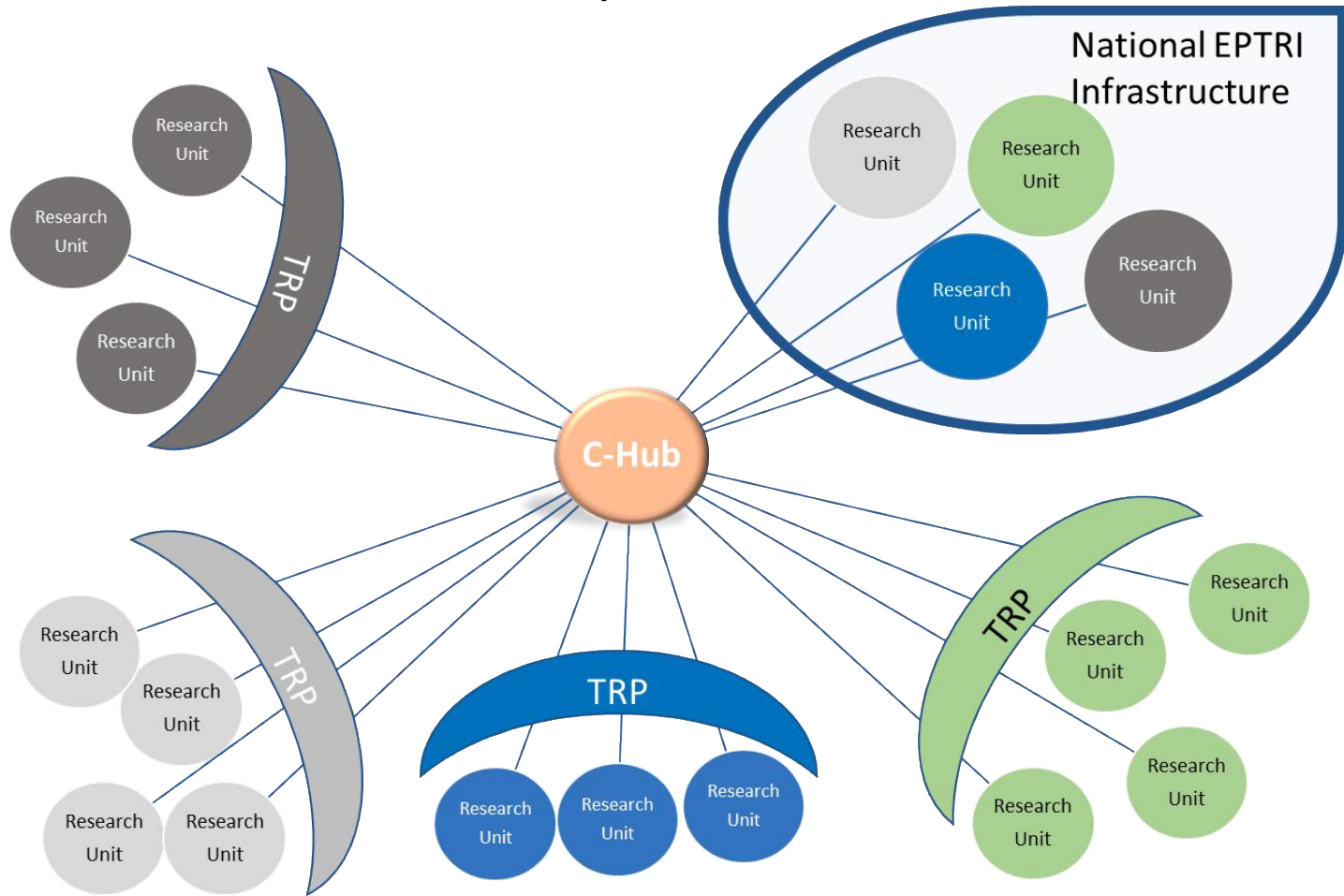
EPTRI Technical Design

EPTRI services:

- **Centralised**
- **Integrated**
- **Common**

EPTRI single access point and centralised services

Requests for service will be received and managed through the **Single Access Point** that will distribute them according to their specificity.
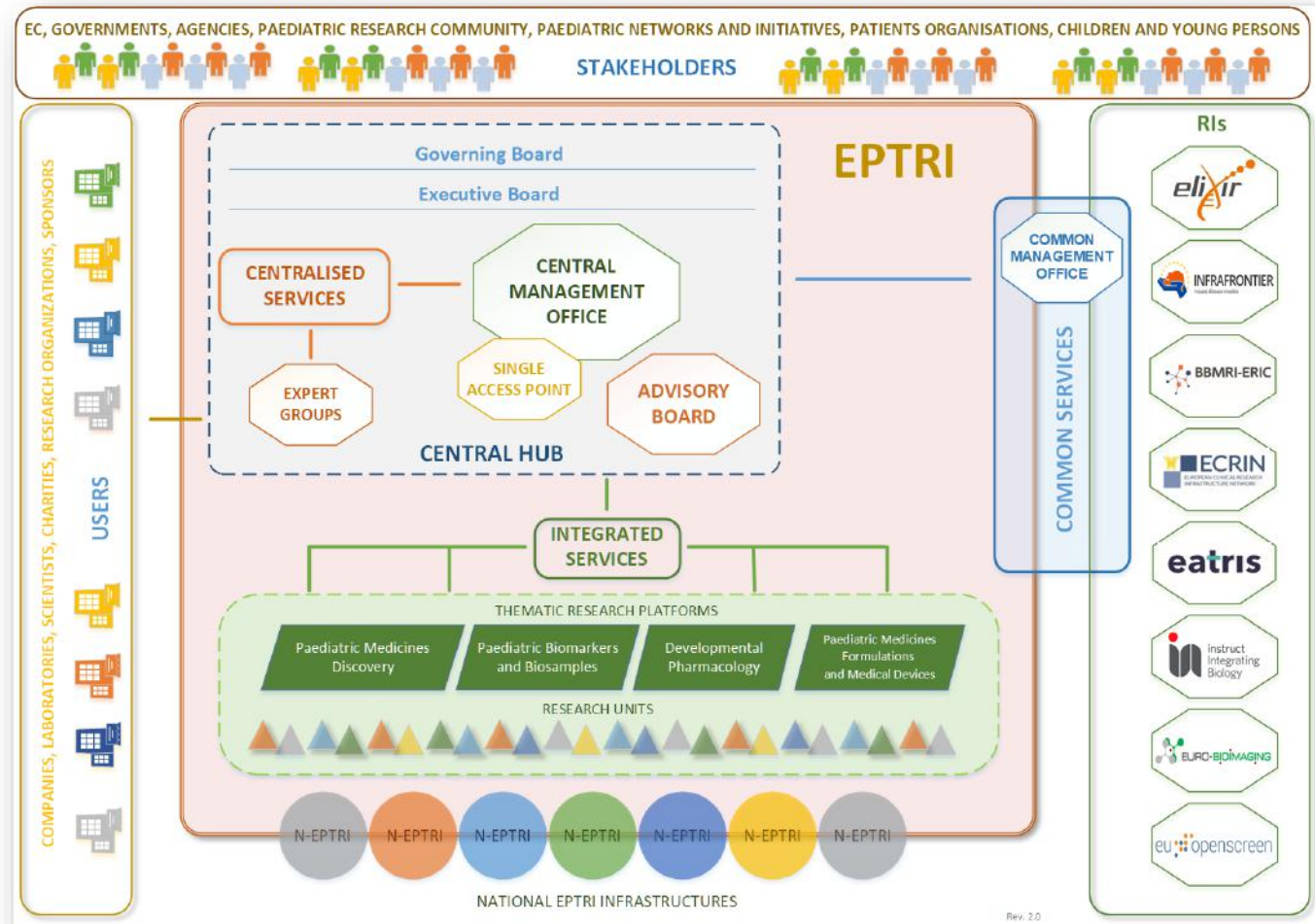
Knowledge and technology transfer

Document Repository and Libraries for scientific documents archiving and consultation

Service for **scouting** of research **funding** opportunities in topics related to the activities of EPTRI

Training and education, including staff exchanges and e-learning modules

Service to provide **scientific advice** on **EPTRI specific issues** (studies dedicated to human development, identification of new strategic lines of interventions, application of new technologies to drug development, etc.)

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Thematic Research Platforms

Integrated Services will be provided through the thematic research platforms where key enabling technologies and expertise are grouped:

1. Paediatric Medicines Discovery
2. Paediatric Biosamples and Biomarkers
3. Developmental Pharmacology
4. Paediatric Medicines Formulations and Medical Devices

The **Thematic Research Platforms** are conceptual operational groups containing a constellation of Research Units to provide Integrated Services

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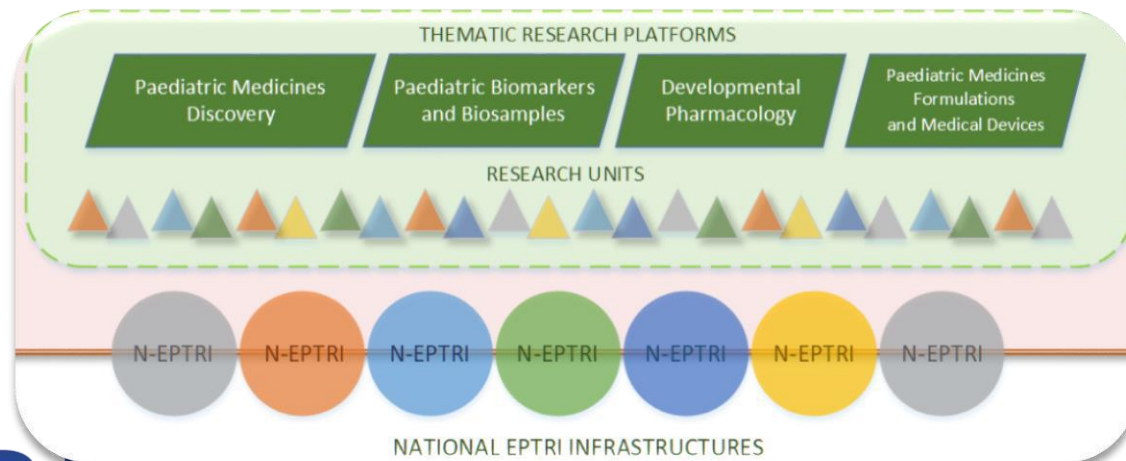
Global outreach and networking

Contacts with:

- initiatives conducted at national and international level dedicated to paediatric research

- EU and non-EU countries not yet part of EPTRI

- existing RIs, which have been surveyed with the aim to investigate how far the needs of the paediatric research communities are met by the existing RIs and thus to avoid any duplication and redundancy

Collaborations with other RIs and in particular with BBMRI on legal, ethical and societal issues that are paediatric specific, and with ELIXIR on 'paediatric interoperability data' have been also investigated.

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Common services

Common service for ELSI support in paediatric research

A common service to ensure ethical, legal and societal support and guidance for those conducting research with children, both biomedical and translational, from the preclinical phase to clinical studies, access policies and education will be developed in collaboration with BBMRI.

Common service for data interoperability in paediatric research

A common service to ensure data interoperability in paediatric research will be created in collaboration with ELIXIR. It will be developed and deployed to facilitate and support use and re-use of data for research purposes, collaboration and sharing of knowledge, experiences and best practices.

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EPTRI Supporter

Scientific community

Patients and patients associations, advocacy groups

Academy and Health Institutions

National/Regional Bodies, including Governments

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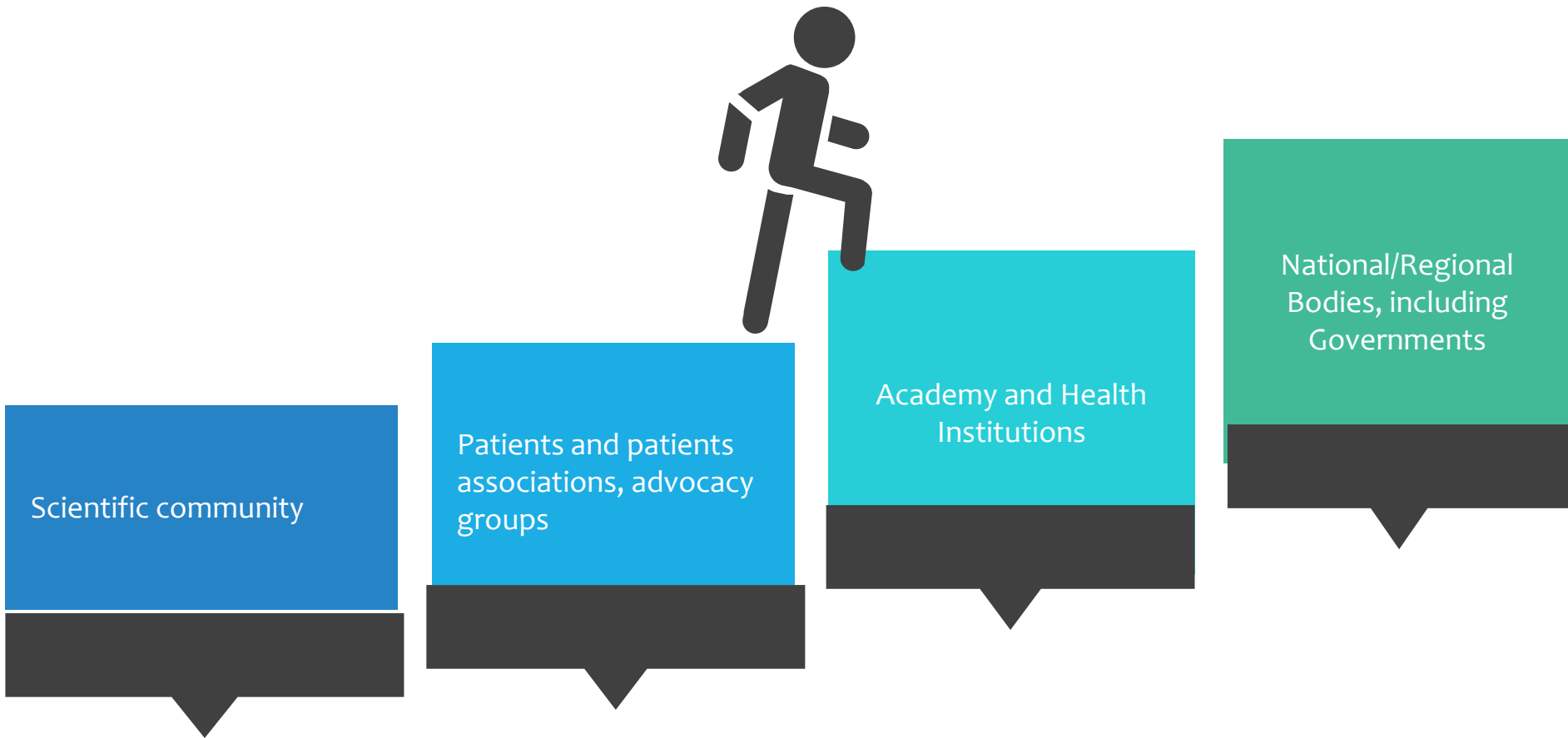
Feasibility studies

Feasibility study proposals have been submitted by internal and external users and assessed by the Project Advisory Board. They would provide information about services/technologies that EPTRI could offer to support the researchers in developing their idea in the translational phase.

EPTRI life cycle

3. PREPARATION
Preparatory Phase, business & construction plan, political and financial support secured, data policy & data management, cost book plan, legal entity identification

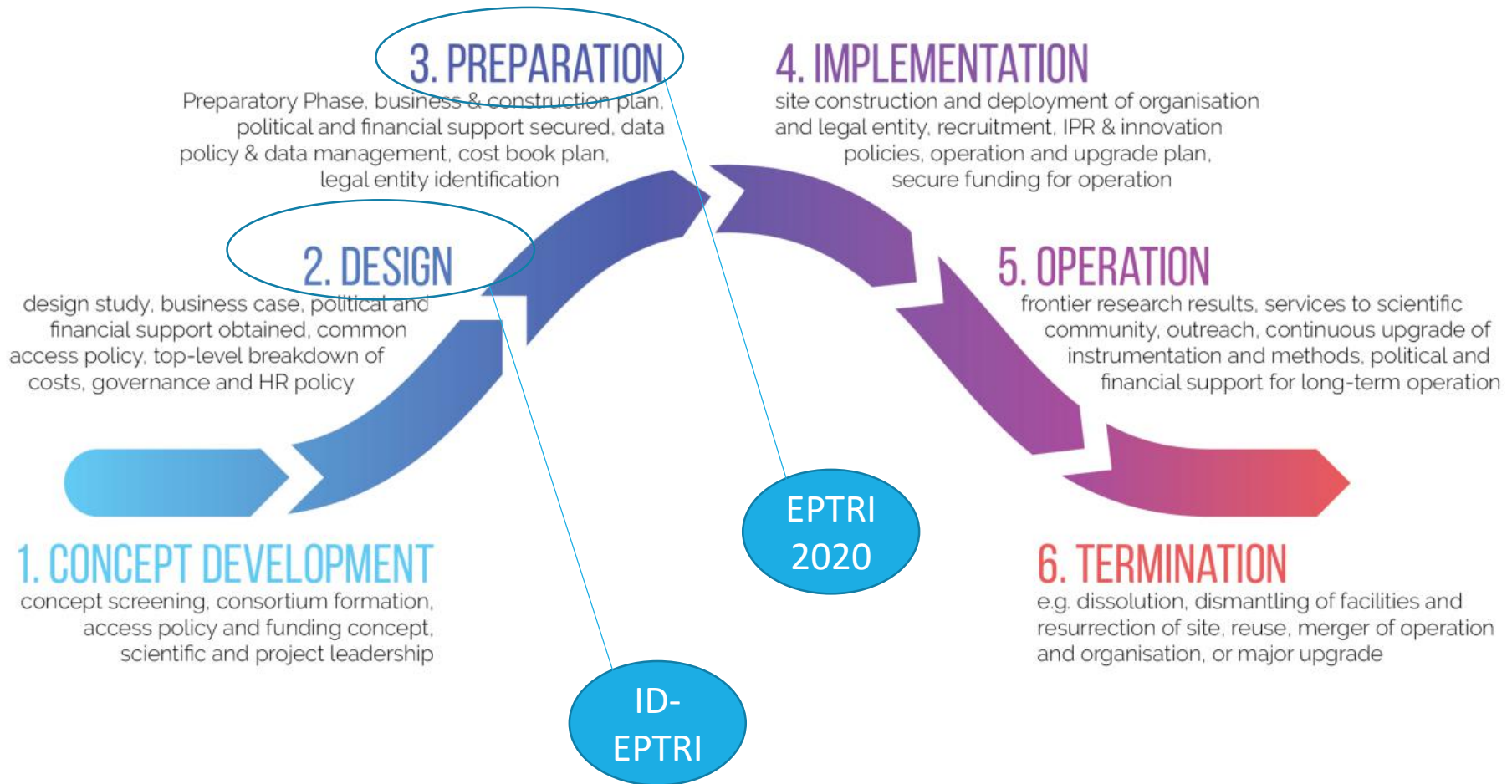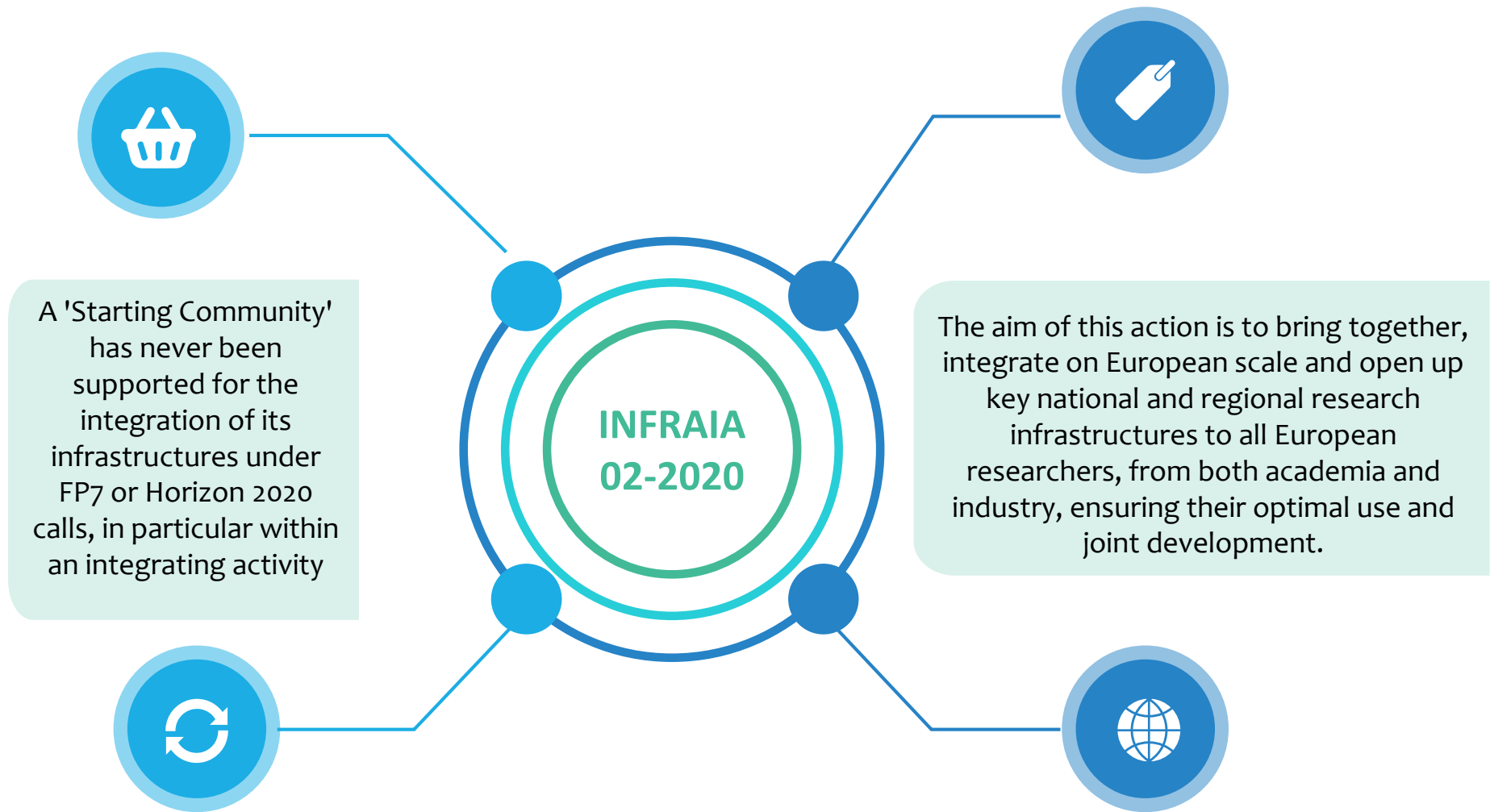**4. IMPLEMENTATION**
site construction and deployment of organisation and legal entity, recruitment, IPR & innovation policies, operation and upgrade plan, secure funding for operation

2. DESIGN
design study, business case, political and financial support obtained, common access policy, top-level breakdown of costs, governance and HR policy

5. OPERATION
frontier research results, services to scientific community, outreach, continuous upgrade of instrumentation and methods, political and financial support for long-term operation

1. CONCEPT DEVELOPMENT
concept screening, consortium formation, access policy and funding concept, scientific and project leadership

6. TERMINATION
e.g. dissolution, dismantling of facilities and resurrection of site, reuse, merger of operation and organisation, or major upgrade

EPTRI 2020

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INFRAIA 02-2020

A 'Starting Community' has never been supported for the integration of its infrastructures under FP7 or Horizon 2020 calls, in particular within an integrating activity

INFRAIA 02-2020

The aim of this action is to bring together, integrate on European scale and open up key national and regional research infrastructures to all European researchers, from both academia and industry, ensuring their optimal use and joint development.

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Integrated activities

Networking activities

To foster a culture of co-operation between research infrastructures, scientific communities, industries and other stakeholders as appropriate, and to help develop a more efficient and attractive European Research Area

Joint research activities

To improve, in quality and/or quantity, the integrated services provided at European level by the infrastructures

Trans-national access or virtual access activities

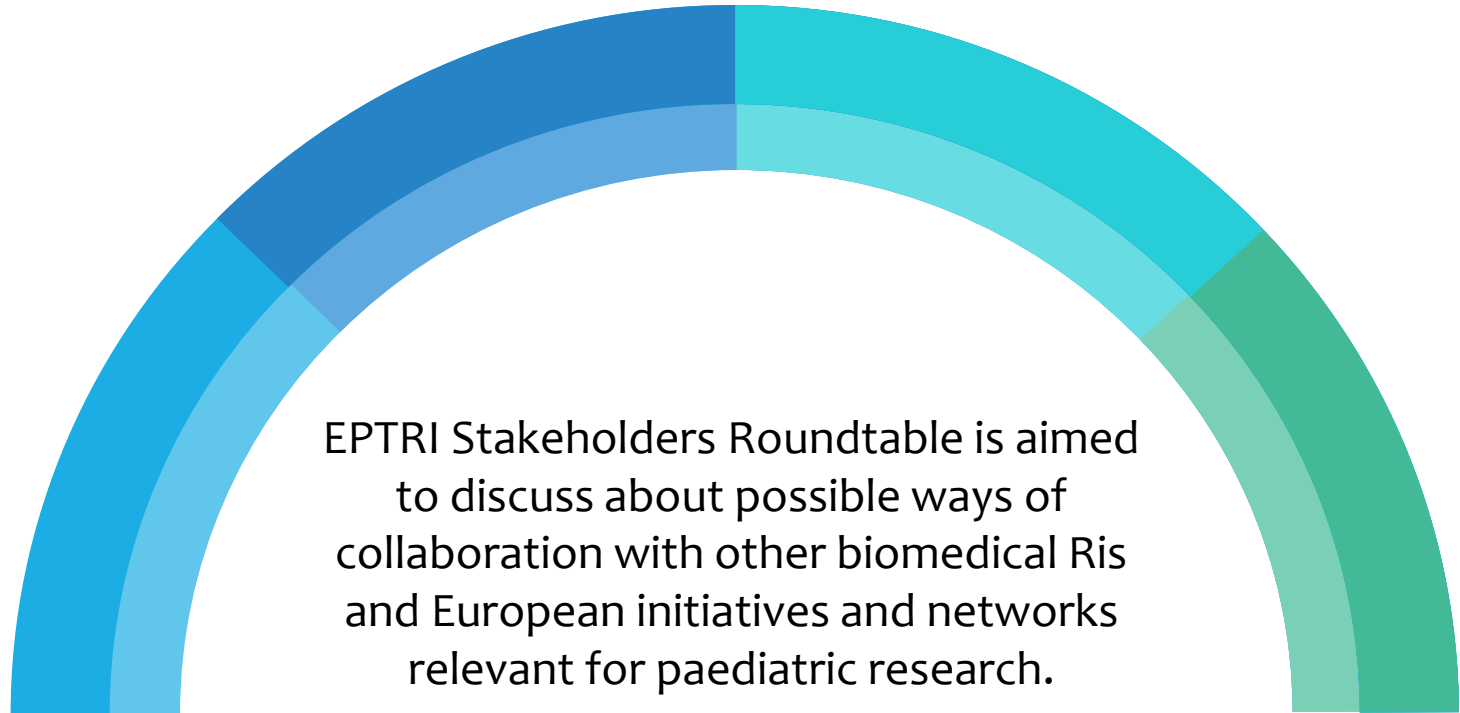To support scientific communities in their access to the identified key research infrastructures

All three categories of activities are mandatory as synergistic effects are expected from these different components.

Budget: 5 MIllion

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EPTRI Stakeholders Roundtable

EPTRI Stakeholders Roundtable is aimed to discuss about possible ways of collaboration with other biomedical Ris and European initiatives and networks relevant for paediatric research.

It will be organised as a discussion around some key documents that will be shared in advance with the invited participants.

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