
ID-EPTRI project

European Paediatric Translational Research Infrastructure

MEETING AGENDA

EPTRI Stakeholders Roundtable
Virtual Meeting July 9th, 2020

EPTRI - European Paediatric Translational Research Infrastructure

EPTRI is an EU funded project aimed to design the framework for a new infrastructure dedicated to paediatric research that will work to accelerate the paediatric drug development processes to facilitate the translation from new paediatric medicines target identification to clinical tests and marketing authorisation.

To achieve this ambitious goal EPTRI promotes a focused approach where:

- the whole medicines developmental process adopts innovative methodologies tailored on the paediatric pharmacological specificities;
- a structured collaboration among different research capacities is established, to cover the research needs of the whole paediatric scientific community in the different research fields.

EPTRI will be established as a **Distributed RI based on a Hub and Spoke operational model**, which allows the Central Hub to maintain a strong role in promoting Networking, Knowledge Translation, Access to the services, also provided in common with other RIs. In this model, the participating Research Units (RUs) will be aggregated in Thematic Research Platforms (TRPs) aimed at delivering Integrated Services, and the Member States will promote the organisation of the local resources within National Nodes (N-EPTRI) able to participate to national and international activities in a coordinated manner.

EPTRI is a pan-European initiative which involves organisations from more than 20 EU and non-EU countries, including non-profit research organisations, top-level universities, scientific and clinical centres of excellence. According to the survey conducted in 2018-2019 to map paediatric research facilities and competences, more than 250 research Institutions declared their availability to provide technologies, services and paediatric expertise, and the majority of them have been already grouped in four **Thematic Research Platforms**:

- Paediatric Medicines Discovery TRP;
- Paediatric Biomarkers and Biosamples TRP;
- Developmental Pharmacology TRP;
- Paediatric Medicines Formulations TRP.

Furthermore, EPTRI Centralised Services will provide advice on the design and requirements of not clinical specific studies/experiments and on translation to clinical phases, acting as a bridge versus paediatric clinical research networks and activities.

In order to be recognised at EU level by ESFRI (European Strategic Forum on Research Infrastructure) and become a fully-fledged RI in the ESFRI landscape, EPTRI needs to receive the political support from the governments. So far, EPTRI has already received letters of political and financial support from the Governments of Italy, Spain, Poland, Hungary, Israel, Albania, Russia and Ukraine, and is working to collect the adhesions of many other countries.

The EPTRI Stakeholders Roundtable is organised as a discussion around some key documents that have been shared in advance with the invited participants as the short version of the EPTRI Conceptual Design Report, the EPTRI lifecycle and expected impact, the results from the EPTRI Stakeholders survey and an outreach plan to link EPTRI to other research initiatives aimed to promote children's health.

Stakeholders from EU Institutions, Governments, European RIs and projects, agencies, networks, ERNs, patients' associations, charities, research organisations and also partners from non-EU countries have been invited to join.



EPTRI Stakeholders Roundtable

AGENDA - 9th July 2020¹

09.30-11.00	SESSION 1: The paediatric research in the European Research Area	
	The EPTRI project and the future of Paediatric Research	D. Bonifazi
	The European Networks for Paediatric Research	P. Lepola
	The Network of parliamentary advocates for paediatrics to promote new scenarios for a better access to medicines	M. Dalli
	The highest challenge of rare diseases in children	L. Sangiorgi
	The patient centered research in the rare and paediatric diseases perspective	D. Athanasiou
	Horizon Europe overview. Paediatric developments and prospects	A. Costescu
11.30-13.30	SESSION 2: The EPTRI conceptual design	
	EPTRI organisation of services, data and access	F. Bonifazi
	Presentation of the EPTRI Technology Research Platforms	E. Mikros M. Phylactides T. van der Geest E. Alessandrini
	EPTRI to Underpin Paediatric Clinical Studies	M. Turner
	EPTRI Feasibility Studies to design the new scenario of paediatric research EPTRI Feasibility Study "Melatonin administered during pregnancy as a potential neuroprotective agent against neonatal brain damage"	A. Ceci E. Jacqz-Aigrain
	The Belgian EPTRI node as an example for an integrated approach to paediatric research	J. Vande Walle

¹ All times refer to Central European Summer Time (CEST)

14.30-15.30	SESSION 3: EPTRI Networking, Outreach and Development	
	EPTRI Outreach and Networking plan	M. Lupo
	EPTRI Toolkit for young patients	B. Nafria
	The creation of a Technology Research Platform on Medical Devices	P. Dimitri
	Open Lab for Robotics and Imaging in Industry and Medicine	M. Henke
	The development of placental research services	F. Staud
	PlaTox - Placenta Toxicology - human placental explants for drug testing	U. Markert
	EPTRI development in EU associated countries	D. Nika

16.00-17.00	SESSION 4: Research Infrastructures in the life science domains	
	How EJP-RD can support paediatric research	D. Julkowska
	Ethical, Legal and social issues in paediatric research: the proposed ELSI service	V. Giannuzzi
	Interest of INFRAFRONTIER in paediatric research	M. Raess
	EU-OPENSREEN - The European Research Infrastructure Consortium for Chemical Biology and early Drug Discovery	B. Stechmann
	Paediatric Data Interoperability common service in collaboration with ELIXIR	P. Martelli
	The ESFRI framework to promote excellence science in Europe	N. Witzanyova
	EPTRI in the ESFRI landmark	G. Migliaccio



EPTRI Stakeholders Roundtable SPEAKERS LIST

Elisa Alessandrini, School of Pharmacy, University College of London

Dimitrios Athanasiou, Paediatric Committee, European Patients Forum

Donato Bonifazi, Consorzio per Valutazioni Biologiche e Farmacologiche

Fedele Bonifazi, Gianni Benzi Pharmacological Research Foundation

Adriana Ceci, Gianni Benzi Pharmacological Research Foundation

Alexandru Costescu, European Commission

Miriam Dalli, European Parliament

Paul Dimitri, Sheffield Children's NHS Foundation Trust

Viviana Giannuzzi, Gianni Benzi Pharmacological Research Foundation

Maria Henke, University of Lübeck

Evelyne Jacqz-Aigrain, Assistance Publique - Hôpitaux de Paris, Robert Debré Hospital

Daria Julkowska, EJP RD coordinator, INSERM

Pirkko Lepola, Helsinki University Hospital, European Network for Paediatric Research at the EMA

Mariangela Lupo, TEDDY European Network of Excellence for Paediatric Research

Udo Markert, Friedrich Schiller University Jena



Pier Luigi Martelli, University of Bologna, ELIXIR-IT

Giovanni Migliaccio, Consorzio per Valutazioni Biologiche e Farmacologiche

Emmanuel Mikros, ATHENA Research and Innovation Center in Information Communication & Knowledge Technologies

Begonya Nafria, Institut de Recerca Sant Joan de Déu, Fundacio Sant Joan De Déu

Daniela Nika, University Hospital Mother Teresa

Marios Philactides, Cyprus Institute of Neurology and Genetics

Michael Raess, INFRAFRONTIER-ERIC

Luca Sangiorgi, ERN-BOND, Rare Skeletal Diseases Department, Rizzoli Orthopedic Institute

Frantisek Staud, Charles University

Bahne Stechmann, EU-OPENSREEN-ERIC

Mark Turner, University of Liverpool

Tessa Van der Geest, Radboud University

Johan Vande Walle, Ghent University

Nadezda Witzanyova, Czech Academy of Sciences

