

EPTRI AISBL

**Equality, Diversity and
Inclusion Strategy, including
Gender Equality Plan**

Introduction: EPTRI AISBL

The European Paediatric Translational Research Infrastructure (EPTRI) started as a project coordinated by Consorzio per Valutazioni Biologiche e Farmacologiche (CVBF – Clinical Validation from Biopharmaceutical Findings) and funded within the H2020-INFRADEV-01-2017 programme, arising from the need to find answers to the serious lack of medicines for children in EU and worldwide. EPTRI is a Research Infrastructure (RI) composed of several research units grouped both within Thematic Research Platforms – TRPs (according to the field of expertise) and National Nodes (according to their location).

There are five TRPs, each managed by two Coordinators and supported by the Central Management Office (CMO):

- **Paediatric Medicine Discovery** - which relates to the early-stage discovery and development of druggable molecular targets specific to paediatric disease, as well as discovery of new drugs using models reproducing specific paediatric populations.
- **Paediatric Biomarkers and Biosamples** - performing research to identify, characterise and validate new biomarkers for diagnosis, prognosis, and personalised therapy in paediatric diseases; provide access to/deposit of annotated paediatric biological samples.
- **Developmental Pharmacology** - concerning studies on the pharmacological characteristics of drugs and related body response, based on the knowledge of growth and development/maturation of the organs and functions.
- **Paediatric Medicines Formulations** - which develops appropriate age-specific formulations and adequate delivery systems for preterm neonates, infants, toddlers, children and adolescents.
- **Paediatric Medical Devices** - to cover the gap in medical devices tailored for children that account for changes in growth and psychosocial maturation, physiology, and pathophysiology, and avoid inappropriate repurposing of adult technologies.

A sixth Platform is dedicated to providing [centralised services](#) which are advice or hands-on activities transversal to the TRPs and intended to support any step of the paediatric research conducted in the basic, pre-clinical and translational setting. Centralised services are directly provided by the EPTRI CMO in collaboration with dedicated experts, research infrastructures and paediatric networks and initiatives.

The research centres and institutions involved in paediatric medicine research identified in the different EPTRI TRPs as Research Units are aggregated in each country through the establishment of National Nodes.

The CMO supports the General Assembly and the Board of Directors (BoD) and the implementation of their decisions. The CMO is entrusted with the day-to-day management of the EPTRI AISBL.

The General Assembly (GA) is the supreme authority of EPTRI AISBL and is composed of one (1) delegate per Member with voting rights. The GA elects the President and the BoD and ensures balance in terms of gender, diversity, geographic coverage, expertise and stakeholder representation. Within the BoD, deliberates by a simple majority of the votes cast by its members present or represented. In the event of a tie, the chairman's vote is decisive.

As of 2024, March 6th, EPTRI is a non-profit research organisation incorporated in the form of an Association Internationale Sans But Lucrative (AISBL) governed by Belgian law, based in Leuven (EPTRI statutes [here](#)), with a mission to connect academic research units with biotech and pharmaceutical companies to promote new technologies adapted to the paediatric setting, accelerate the development of tailored solutions for the paediatric population and implement innovative collaborative models to lower the entry barrier for novel tools and practices.

With the acquisition of the legal status, EPTRI is open to new members and additional countries and strengthens contacts with relevant stakeholders, including patients, companies and regulators.

EPTRI aims at:

- Promote and accelerate access to the large portfolio of paediatric EPTRI research services.
- Enhance synergies and pooling skills of paediatric research centres of public and private Institutions in charge to provide the EPTRI services.
- Promote collaborative activities with Networks, Partnerships, ERNs, RIs, EU funded projects and other initiatives that might be beneficial to enhance paediatric research.
- Support Academia and research organisations to strengthen their base knowledge and technological know-how.

EPTRI is based on international experts' collaboration supported by a small staff group covering day by day activities, including financial, project management and communication. The organization takes into high consideration the visibility of women, as confirmed by the overall high female quotas, in the staff members, including permanent and contract employees, as well as in the CMO and within the Coordinators of the TRPs.

EPTRI's – Equality, Diversity and Inclusion Strategy (EPTRI's - EDIS) including Gender Equality Plan

Equality, diversity and inclusion are fundamental values of the European Union. Equality, diversity and inclusion benefits research and innovation (R&I) by improving the quality and relevance of R&I, attracting and retaining more talent, and ensuring that everyone can maximise their potential by having the same opportunities, and that no-one is treated differently or discriminated against because of their personal characteristics. EPTRI is committed to fostering an inclusive culture which promotes equality, values diversity and maintains an environment in which the rights and dignity of all members are respected.

At EPTRI everyone must be treated equally based on their merits and relevant objective criteria, regardless of age, disability status, ethnic or national origin, sex, sexual orientation, gender identity, race, socioeconomic background, political or religious beliefs, or family circumstances including pregnancy, parental status, marriage and civil partnership (Chapter 3 of the [EU Charter of fundamental rights on equality](#)). By doing so, EPTRI is ensure equal representation of:

- senior and junior researchers/members,
- female and male members/workers,
- diversity groups.

Furthermore, EPTRI is also engaged in promoting patient and public involvement (PPI) in its activities, which means working in collaboration with patients, caregivers, service users, families, people with lived experience, or the public, in planning, designing, managing, conducting, disseminating and translating research. ¹ By integrating PPI representatives/contributors, EPTRI will improve the quality, the value and the impact of

¹ [Guide no 8: Patient and Public Involvement in HSE Research - https://hseresearch.ie/patient-and-public-involvement-in-research/](https://hseresearch.ie/patient-and-public-involvement-in-research/)

paediatric research. By closely collaborating with the TEDDY Network and the young person advisory groups – KIDS Bari and KIDS Albania – EPTRI will ensure the inclusion of patients' voices and points of view.

Regarding specifically, gender equality, in 2021, the European Commission encouraged the establishment of a Gender Equality Plan (GEP) (following the [Guidance](#)) as an eligibility criterion for all public bodies, higher education institutions and research organisations to participate in the Horizon Europe Framework Programme. A GEP is a set of commitments and actions that aim to promote gender equality in an organisation through institutional and cultural change. To this end, EPTRI drafted a 3-year period plan for the period 2024-2026, with the goal to more closely implement actions and measures to improve its internal gender equality practices, hence, EPTRI's GEP is a programmatic document that looks at the first three years (2024-2026) of the EPTRI AISBL activities with the aim to implement actions and projects to reduce gender asymmetry and, at the same time, allows the enhancement of all diversities.

Currently within EPTRI the CMO, composed of 9 members has 55,5 % of women and the BoD composed of 21 members has a percentage of 33,3 % of women. Despite the higher number of women in the CMO, there is room for improvement in the gender balance within the BoD.

The present document is the formal statement in which EPTRI's engagement for gender equality is formalised into a GEP. Thus, this document represents EPTRI's commitment of supporting gender equality along with maintaining and improving the measures and actions necessary to achieve this goal.

Measures in EPTRI's GEP

Publication and official endorsement of EPTRI-GEP

According to the EU mandatory requirements, EPTRI GEP is published on the organisation's website, circulated among its members and officially endorsed by the members of the Board of Directors.

Dedicated resources

EPTRI owns dedicated resources to commit to the set-up, implementation and monitoring of the plan. EPTRI has set up a working group for the realization of its GEP and the

implementation of the 3-year plan. The goal of this working group is to obtain a truthful picture of the main gender characteristics within the profiles and career paths within the organization. At the same time, specific activities have been planned to collect and analyse EPTRI's actions to support equal opportunities among its staff as stated in this document. This analysis will be the precondition for further contributions to ameliorate EPTRI gender policies. In such perspective, the appointed team will ensure the implementation of the GEP's measures and actions and engage stakeholders to achieve this goal.

Data collection and monitoring

Disaggregated data on the sex and/or gender of the personnel, including the CMO and TRPs, will be collected and included in the annual report. The most suitable indicators relevant to the activities and responsibilities of the personnel within the organisation, namely gender mainstreaming, the status of commitment to the promotion of gender equality, and gender balance in human resources, will be selected to oversee gender equality and monitor the progress, according to the [Belgian Gender Mainstreaming Law and the Belgian Gender Act](#).

Training

Training activities focusing on raising awareness on gender issues will be regularly organised among the personnel of the entire organisation to ensure people's engagement in implementing inclusive approaches in the daily working environment.

Planning Phase

The EPTRI GEP respects the 5 major areas as indicated by the European Commission, Directorate-General for Research and Innovation, and [Horizon Europe guidance on gender equality plans 2021](#). In EPTRI's GEP each specific area is organised in distinct objectives and a set of expected results have been identified to ensure the achievement of final goals, such as reaching real gender balance. Associated to each expected result, actions to be carried out over the next 3 years have been identified. At the same time, the related achievement indicators useful for the monitoring process have been highlighted as following:

1. Work-life balance and organisational culture
2. Gender balance in leadership and decision-making

3. Gender equality in recruitment and career progression
4. Integration of the gender dimension into research and teaching content
5. Measures against gender-based violence, including sexual harassment

1. Work-life balance and organisational culture

Focus Area	Action	Indicator	Timeline
GEP working group	Establish a permanent working group for gender equality to implement actions reported in the GEP and monitor their impacts.	Nr. of actions reported in the GEP Action plan timely implemented.	2024
Flexible working time arrangements	Current adoption of agile working mode for staff members and possible improvements.	Number of staff members who work in remote working mode.	2024-2026
Workload management	Equal allocation of tasks among the personnel during significant workload periods.	Number of tasks individually assigned to the personnel.	2024-2026
Support on work-life balance	Improvement of measures (remote working, part-time working hours) already in place to assist reintegration of the staff after leaves for personal reasons, parental commitments or career breaks. Additionally, the return to work will be organised to address care commitments-related issues.	Annual personnel satisfaction surveys (work-life balance, physical and mental health, fair treatment, trusted people to work with).	2024-2026
Raising awareness of GEP	Provide a copy of the EPTRI AISBL GEP to the new assets.	100% of staff members who are provided with a copy of the EPTRI AISBL's GEP.	2024-2026

2. Gender balance in leadership and decision-making

Focus Area	Action	Indicator	Timeline
Gender balance leadership in decision-making	<p>Strong visibility of women in leadership positions and participation is already occurring within the organisation.</p> <p>A gender balanced composition is going to be maintained in the CMO, the Board of Directors and the TRPs Coordinators.</p>	<p>Ensuring no prevalence of one gender in the CMO, the Board of Directors and the TRPs Coordinators. Selection procedures to balance gender quotas may be evaluated especially in view of a future expansion of the staff.</p>	2024-2026

3. Gender equality in recruitment and career progression

Focus Area	Action	Indicator	Timeline
Equal opportunities in recruitment and in career development and progression	<p>Internal procedures are already in place to ensure that equal criteria are adopted in the recruitment process and career development and progression.</p>	<p>Establishment of gender-balanced candidate pools and monitoring of career development and progression opportunities.</p>	2024-2026

4. Integration of the gender dimension into research and teaching content

Focus Area	Action	Indicator	Timeline
Gender balance into research and teaching content	Procedures are running to maintain and enhance the presence of women researchers in the activities managed by the organisation (e.g., scientific publications, research projects, scientific conferences meetings, webinars, and institutional communication). Monitoring procedures will be defined, and initiatives and other communication activities implemented.	Number of initiatives/ activities in which the gender balance criteria have been adopted.	2024-2026
Initiatives in support of gender equality	Organisation of initiatives during public awareness days (e.g. International Women's Day, 8 March; International Day of Women in Science, 11 February, etc.), and enhancement of internal communication to better engage the staff members.	Number of awareness days communicated per year to staff members.	2025-2026
Collection of research data on gender balance	Scientific findings obtained from males do not always apply to females and vice-versa, furthermore, gender disparity in paediatric care may lead to gender bias, thus sex differences in diseases, and treatment development and response, will be acknowledged in paediatric research studies.	Number of publications that acknowledge gender differences in health and disease.	2026

5. Measures against gender-based violence, including sexual harassment

Focus Area	Action	Indicator	Timeline
Harassment and gender-based violence	<p>Development of a Consensus Statement that condemns any form of gender-based violence.</p> <p>Measures to prevent sexual harassment will be put in place (i.e., training staff members to alert in case of any suspected harassment or violence occurring; establishment appropriate reporting procedures and disciplinary actions).</p> <p>Establishment of an “anti-violence” coordinator.</p>	<p>Preparation of a Consensus Statement.</p> <p>Staff members’ views on the efficacy of the policy, and on the extent to which their organisation has put the procedure into practice.</p>	2025-2026
Establishment of an “anti-violence” Coordinator	<p>Select a person responsible that will collect complaints on violence and mobbing episodes. This may discourage such behaviours to happen, at the same time, the victim will feel supported to report the incident.</p>	<p>Nr. of staff members that how have contacted the “anti-violence” Coordinator.</p>	2025-2026

Last updated version June 2024

Approved by EPTRI President

ON BEHALF OF THE BOARD OF DIRECTORS

Karel Allegaert