

# Annual Report 2023

December 2023

In 2023, the EHC Think Tank had a bustling year, managing four ongoing workstreams and organising its inaugural face-to-face workshop in Brussels, Belgium. Throughout the year, we conducted a total of 18 virtual workshops dedicated to the Registries, Patient Agency, Access Equity, and Future Care Pathways workstreams.

The Access Equity and Future Care Pathways workstreams began their efforts in early 2023. Workstream members collaborated extensively, actively seeking to understand the root causes behind the current challenges in their specific thematic areas. We were thrilled to host members from the Registries and Patient Agency workstreams at the Innovation Summit in Brussels in June 2023. Employing design thinking approaches, each workstream developed its selected concepts with the guidance of seasoned facilitators and external advisors. You can find further details about each workstream in the sections below and on <a href="https://example.com/englished-com/engl

We want to express our sincere gratitude to the workstream members for their invaluable contributions. Additionally, we extend our heartfelt thanks to the Think Tank Council and Faculty for their exceptional guidance in shaping the thematic focus and employing methodologies.



## Workstream on registries

The Registries workstream aims to better align registries on bleeding disorders across Europe and beyond. It is perceived that alignment will foster greater opportunities for data sharing, improve data quality, and optimise data collection, to mention a few.

Ultimately, more alignment of registries and data should enable us to answer scientific questions with more data and thereby evolve our understanding of the diseases that can lead to better treatment and

Read more: ehcthinktank.eu/workstream/workstream-one-registries/

## Workstream on patient agency

Patient agency refers to the patient's ability to act. It is a concept that encompasses all levels of patient engagement in light of people's preferences, behaviours, and mindsets.

The workstream has dived into diverse aspects where patient agency is relevant, such as more equal collaboration between stakeholders, patient experience data or real-world data, and training and education of stakeholders in the healthcare system to have a broader understanding of people who are also patients.

Read more: <a href="mailto:ehcthinktank.eu/workstream/patient-agency">ehcthinktank.eu/workstream/patient-agency</a>

# Workstream on access equity

In Access Equity, 'access' refers to the ability to benefit from a thing, either financial, physical, etc., while 'equity' refers to the quality of being fair and impartial across and within countries as well as on community and individual levels.

This workstream has identified narrative and behaviour as two key aspects of why access equity is lacking, and is currently exploring what it will take to change the narratives and behaviours leading to fairer access to treatment and care.

Read more: <a href="mailto:ehcthinktank.eu/workstream/workstream-four-access-equity/">equity/</a>

Thank you to Forum for the Future, HaemNet, Overlap, and Phorix Limited for their distinguished collaboration.

### Workstream on future care pathways

The Future Care Pathways workstream is keen to uncover which perspectives are crucial to consider when working on care pathways At the centre of their exploration are:

- How to combine digital and human elements in one pathway:
- How problematic behaviours, nudges, and incentives prevent the care pathway from improving;
- The importance of data-driven pathways to document the current process and facilitate improvements of care pathways.

Read more: ehcthinktank.eu/workstream/workstream-five-future-care-nathways/

Thank you to our grant providers, BioMarin, CSL Behring, Novo Nordisk, Pfizer, Roche, Sanofi, Sobi, and Takeda, for supporting the Think Tank this year. The 2023 Innovation Summit was kindly supported by BioMarin, Pfizer, and Sanofi.