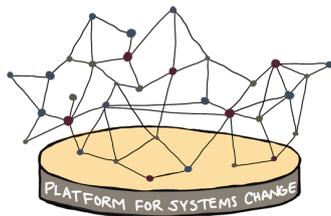


# Annual Report 2022

December 2022



In 2022, the EHC Think Tank hosted 12 workshops for the three running workstreams on registries, the hub & spoke model, and patient agency.

Over the course of the year, all workstream participants collaborated, listened, and actively engaged in trying to uncover the structures, patterns, and mental models underlying their respective thematic areas and potentially feeding into current challenges. You can find more information about each of the workstreams in the boxes on the right and online.

In tandem with the workstreams, we ran an innovation lab consisting of surveys, workshops, and meetings undertaken to learn from different stakeholders about their perspectives on relevant themes to tackle in the EHC Think Tank workstreams. This led to two new workstreams on access equity and future care pathways, respectively, which were launched at the inspirational virtual public event in June, which gathered more than 50 people.

At the organisational level, we grew our internal staff base and launched our own website with information about the thematic work and articles about key concepts, e.g., social innovation, behavioural science, and systems change.

The Think Tank is constantly evolving and received outstanding guidance from its Council and its Faculty in terms of the thematic focus and utilising methodologies.

## Workstream on registries

This workstream seeks to untangle the complexities of registries, to find common ground, and to co-construct a collectively endorsed forward direction, particularly in the areas of:

- The role of the patient in data collection
- The role of healthcare providers in data collection
- Data quality
- Data sharing
- Multiplicity of registries
- Lack of common purpose
- Sustainable funding to develop and maintain registries

See more on:

<https://ehcthinktank.eu/workstream/workstream-one-registries/>

## Workstream on the hub & spoke model

The hub & spoke model workstream explores future treatment pathways, building on international calls for a hub-and-spoke model approach, particularly in terms of how to manage:

- Delivery of gene therapy
- Resource allocation
- Criteria for hubs and spokes
- Collaboration between hub and spokes
- Knowledge distribution
- Re-envisioning delivery of treatment in the future

See more on:

<https://ehcthinktank.eu/workstream/workstream-two/>

## Workstream on patient agency

The workstream on patient agency addresses how to meaningfully embed and integrate patient expertise up-front and throughout the design, organisation, implementation, and evaluation of treatment and care as well as capturing and utilising patient preferences.

Besides working on a definition of patient agency incorporating behaviour, the group identifies the patient's role as a key challenge to ensure that health care is collaborative and based on patients' ability to make choices.

See more on:

<https://ehcthinktank.eu/workstream/patient-agency/>

Thank you to Copenhagen Economics, Forum for the Future, HaemNet, OPEN Health, Overlap, Phorix Limited, and The Synergist for their distinguished collaboration.

Thank you to our grant providers, BioMarin, CSL Behring, Novo Nordisk, Roche, Sanofi, Sobi, and Takeda, for supporting the Think Tank this year.