

Personal Health Train Implementation Network

Introduction

The undersigned represent major public and private stakeholders in health, healthcare and biomedical research, who are currently developing the '[Personal Health Train](#)' (PHT). This is a distributed infrastructure that enables the use and reuse of health data for the benefit of individuals and society. The PHT aims to advance health, healthcare and biomedical science through a shared infrastructure to support data management (healthcare data, health & lifestyle data, and biomedical research data), data analysis, and medical decision making. The PHT is a [GO FAIR](#) Implementation Network (IN). This manifesto is a formal statement of the principles that guide the PHT development.

Empowering citizens

We recognise the increasingly important role of data in supporting citizens navigating their own health and well being, and in the prevention and treatment of disease. The PHT empowers citizens to have control over their own data, to partner with healthcare providers in medical decision making, and to support citizen-initiated research. It respects the autonomy and privacy of citizens and implements important aspects of responsible data science.

We therefore commit to the following **guiding principles** for the development of the PHT:

- **Control over data.** The PHT empowers citizens, public and private organisations to manage, safeguard, and share their data for (re-)use in health, healthcare and scientific research.
- **Reusable health data.** The PHT is a common digital infrastructure for (re)use of health data based on standards and protocols adhering to the [FAIR principles](#).
- **Distributed and federated solutions.** The PHT architecture enables distributed and federated data, which permits data to stay where they are and be processed at their location of origin where possible.
- **Responsible use of health data.** The PHT enables trust and ensures the responsible use of sensitive and/or personal data by adopting international principles and regulations¹.
- **Ethics-by-design.** The PHT enables assessment of compliance with the ethical aspects of data use and enables blocking and reporting abuses of personal and/or sensitive data.
- **Machine-readability at the core.** We focus on creating machine-readable and interpretable data, metadata, workflows, and services, aiming for maximal interoperability between diverse systems.

¹ including the [FACT](#) principles (Fairness, Accuracy, Confidentiality, Transparency), [privacy-by-design](#), privacy-by-default, and the General Data Protection Regulation ([GDPR](#))

Though we appreciate diversity, especially in the research field, we consider this joint statement a way to speak with one voice on a number of critical issues that are of generic importance and on which we feel we have reached consensus. We will therefore coordinate our investments in and support of the technological and social developments in the distributed management and analysis of personal health data.

Targeted Objective for the IFDS covered by the PHT IN

1. The main **goal** of the PHT IN is a set of standards, guidelines, specifications and reference implementations of the core components of the PHT that will allow independently developed implementations to be interoperable among themselves.

Membership list

We consider this Manifesto to be one way by which the undersigned stakeholders can **speak with one voice** on a number of critical issues that are of generic importance to the objectives of FAIR, and on which we feel we have reached consensus. We commit to comply with the Rules of Engagement of GO FAIR Implementation Networks. We will work as a distributed network with regular GO FAIR meetings.

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