

Workshop #2

Interoperability

Session 1

Workshop #2 Session 1

Some information for a smooth running of the session.



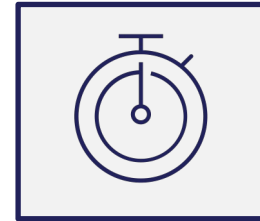
The audio of the session is recorded.
Please only speak in the microphone.



Please introduce yourself every time before speaking.
Do not hesitate to participate and ask questions.



Avoid using your smartphones and laptops if possible.



Please make sure to respect the time allocated for your speech & keep your interventions under 1mn.
Please be on time to the next session.

Workshop #2 Session 1

Facilitators

Eric DURBIN - Kentucky Cancer Registry

Johanna GODERRE - US National Cancer Institute

Subthemes

- Identify systems that need to be interoperable for successful data sharing
- Are there specific formats/ data models/systems (cloud analysis) that might be optimal?

Interoperability has many levels

Analysis

- Analyze data in the same way

Semantic

- Use concepts that have the same meaning

Syntactic

- Data are structured in the same, consistent ways

Services

- APIs and services that leverage interfaces and other levels

Transport

- Data are moved using consistent, secure, reliable methods

Security

- Data sharing and use are managed with equivalent security and privacy controls across partners and according to requisite standards within a single environment

Infrastructure

- Data are managed and stored consistently

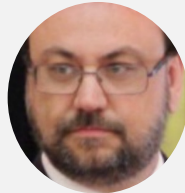
Discussants



Peter GOODHAND

Canada

**Global Alliance for Genomics
and Health (GA4GH)**
CEO



Jan NYGÅRD

Norway

Cancer Registry of Norway
Head of the Registry
Informatics Department

THE GA4GH MISSION...

The **Global Alliance for Genomics and Health** aims to accelerate progress in genomic science and human health by developing standards and framing policy for responsible genomic and health-related data sharing.

Since data is distributed globally, we need interoperable standards to answer research questions





Universal Declaration of Human Rights

(1948)

27(1)

“The Right to
Science”

“Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and **to share in scientific advancement and its benefits.**”

27(2)

“The Right to
Recognition”

“Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.”



Framework for Responsible Sharing of Genomics and Health-Related Data

ga4gh.org/framework

Translated into
14 languages



FOUNDATIONAL PRINCIPLES

- Respect Individuals, Families and Communities
- Advance Research and Scientific Knowledge
- Promote Health, Wellbeing and the Fair Distribution of Benefits
- Foster Trust, Integrity and Reciprocity



AIMS OF THE FRAMEWORK

- Foster responsible data sharing
- Protect and promote the welfare, rights, and interests of groups and individuals who donate their data
- Provide benchmarks for accountability
- Establish a framework for greater international data sharing, cooperation, collaboration, and governance

Universal Declaration
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to
Recognition”

GA4GH Driver Projects



Global Alliance
for Genomics & Health



All of Us Research Program



Autism Sharing Initiative



European Joint Programme - RD



ClinGen



CanDIG



European Genome-phenome Archive



H3Africa



Genomics England



Australian Genomics



Variant Interpretation for Cancer Consortium



Human Cell Atlas



ELIXIR Beacon Project



ELIXIR Cloud & AAI



NCI CRDC



Matchmaker Exchange



Epishare



ICGC ARGO



Monarch Initiative



NHLBI BioData Catalyst



Biomedical Research Hub



Roche imCORE Hub



Human Pangenome Project



International Precision Child Health Project



Repository of the International Fetal Genomics Consortium



NIH Cloud Platform Interoperability Effort



Qatar Genome of Qatar Foundations
Pending



EOESC4Cancer
Pending



Genomic Data Infrastructure
Pending

Cancer Driver Projects



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for Genomics & Health



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H3Africa



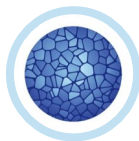
Genomics England



Australian Genomics



Variant Interpretation for Cancer Consortium



Human Cell Atlas



ELIXIR Beacon Project



ELIXIR Cloud & AAI



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NIH Cloud Platform Interoperability Effort



Qatar Genome of Qatar Foundations
Pending



EOsC4Cancer
Pending



Genomic Data Infrastructure
Pending

National Initiatives forum members

Founding members:



Different approaches to data sharing



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for Genomics & Health



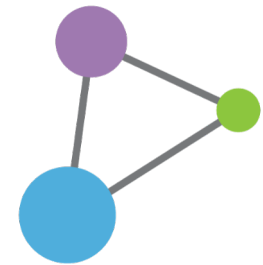
**Centralized
genomic
knowledge bases**



**Data commons
TREs/SDEs**
Trusted, controlled
single repository of
multiple datasets



**Hub and spoke
federation**
Common data
elements, structures,
access, and usage rules



**Linkage of
distributed and
disparate datasets**

Federation: a solution for data analysis



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No data copying or
transfer



Data can remain in
original jurisdiction



Ownership and access
control retained

A new paradigm for data sharing



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FROM



Data copying



TO

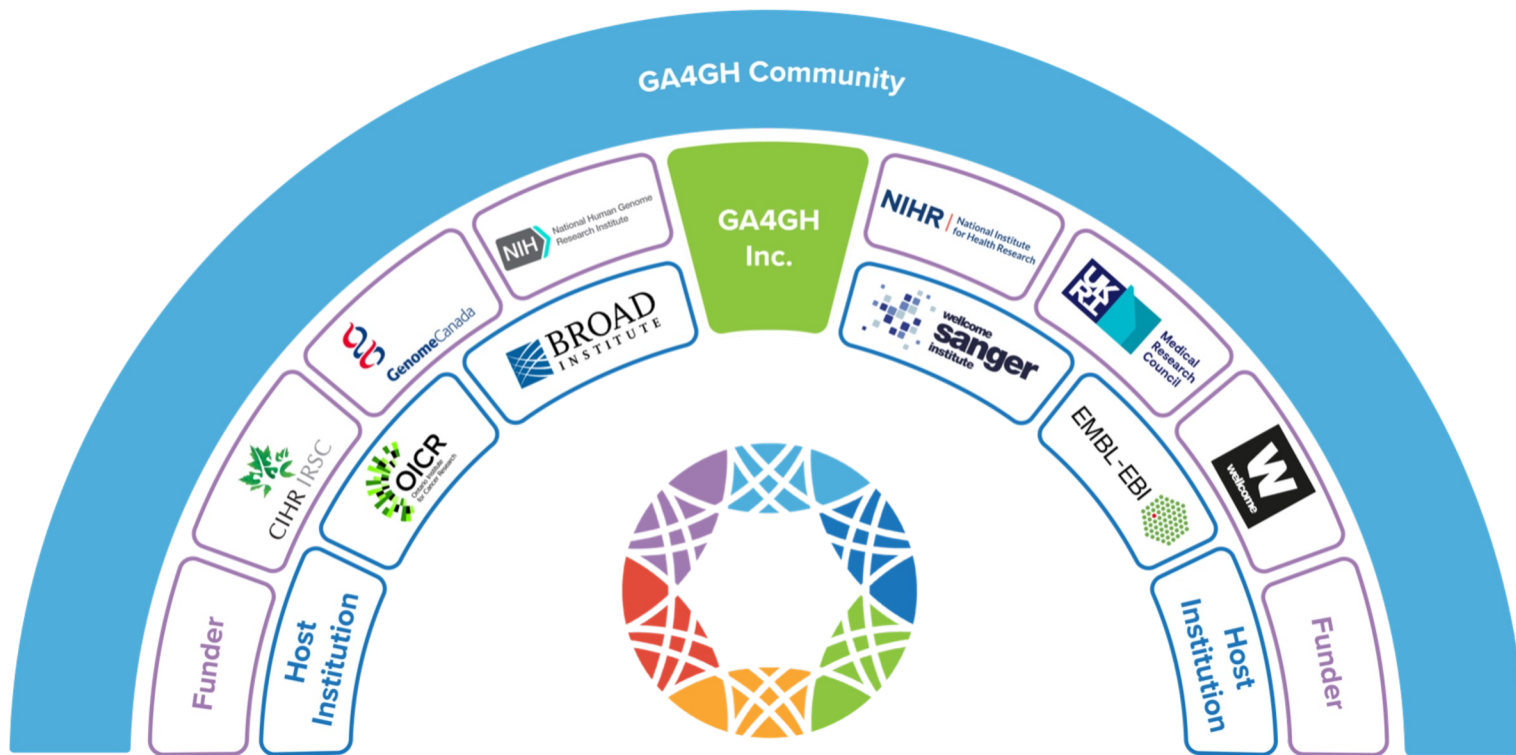


Data visiting

GA4GH Entities and Funders



Global Alliance
for Genomics & Health



Norwegian Clinical Childhood Cancer Registry and Nordic Collaboration

Workshop – Session 1
Interoperability

Jan F Nygård
Cancer Registry of Norway

Norwegian Childhood Cancer Registry

- *Cancer in children is rare, in 2022 there were 210 new registered cancer cases for children in the age group 0-17. Children have equally good prospects of recovery no matter where in Norway they live.*
- The Norwegian Childhood Cancer Registry registers cancer in children under the age of 18. The registry has existed since 1985 and the Cancer Registry of Norway is responsible for data processing. All doctors who provide health care to children with cancer are obliged to report to the Cancer Registry, which includes the Norwegian Childhood Cancer Registry.
- The Norwegian Childhood Cancer Registry registers information on assessment, treatment and follow-up of this patient group. Detailed information on cases of cancer registered according to the classification system ICC3 (International Classification of Childhood Cancer).
- To encourage reporting, administrative and clinical statistics have been compiled that provide hospitals with updated results for their unit. These statistics are updated daily.
- There is extensive cooperation in the Nordic countries and internationally between the academic communities to improve the situation for children who get cancer. We are now seeing improved assessment and treatment and an ever-improving registration of almost all cases of cancer in children and adolescents in the Norwegian Childhood Cancer Registry.

Key figures - childhood cancer 2022

Number of new cases

210 children (0-17 years)

Rates - number of cases per 100,000

- 18.8 Children

5-year survival (2013-2022)

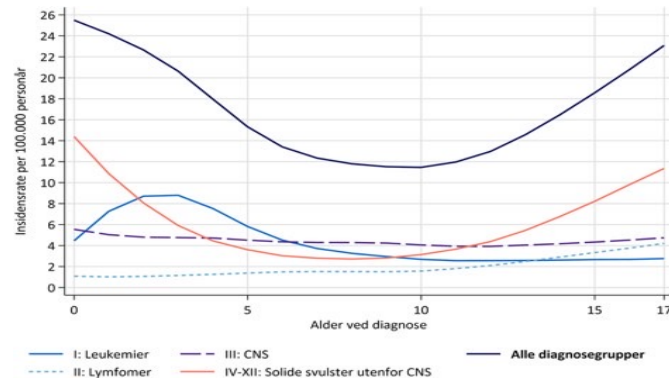
88.9%

Cancer survivors

6,912 children as of 12/31/2022

Death

27 children*



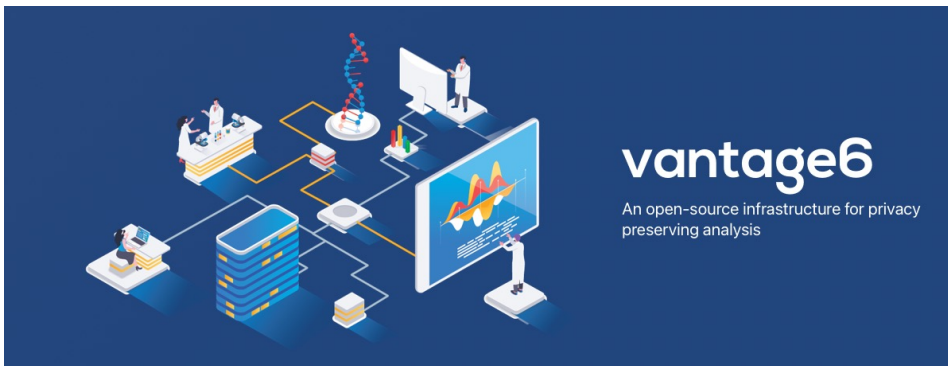


Nordic Society of Paediatric Haematology and oncology

NOPHO, The Nordic Society of Paediatric Haematology and Oncology was founded in the beginning of the 1980s by a group of enthusiastic friends with the ultimate goal to increase survival for children with cancer.

Since then NOPHO has grown into a big family including members from the Nordic and Baltic countries with increasing collaboration with other international groups such as I-BFM, ITCC, PaeNNO, SIOP and SIOP Europé.

The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) & Vantage6



SPECIAL SERIES: CANCER CLASSIFICATION SYSTEMS

Extending the OMOP Common Data Model and Standardized Vocabularies to Support Observational Cancer Research

@review articles

Rimma Belenkaya, MA, MS¹; Michael J. Gurley, BA²; Asieh Golozar, MD, PhD³; Dmitry Dymshyts, MD⁴; Robert T. Miller, MS⁵; Andrew E. Williams, PhD⁶; Shilpa Ratwani, CS, MBA⁷; Anastasios Siapou, MS⁸; Vladislav Korsik, MD⁹; Jeremy Warner, MD, MS⁹; W. Scott Campbell, PhD, MBA⁹; Donna Rivera, PharmD, MS¹⁰; Tatiana Banokina, MS¹¹; Elizaveta Modina, MS¹¹; Shantha Bethusamy, MS¹¹; Henry Morgan Stewart, PhD¹²; Meera Patel, MD¹³; Ruijun Chen, MD, MA¹¹; Thomas Falconer, MS¹¹; Rae Woong Park, MD, PhD¹²; Seng Chan You, MD¹²; Hokyun Jeon, MS¹²; Soe Jeong Shin, MS¹²; and Christian Reich, MD, PhD⁷

CONTEXT

Key Objective

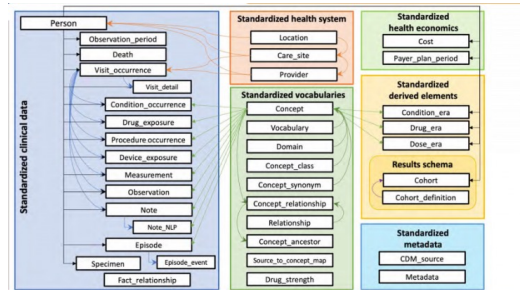
To develop an extension of the OMOP Common Data Model and Standardized Vocabularies to support the comprehensive representation of cancer conditions, treatments, and disease abstractions required for addressing key research questions.

Knowledge Generated

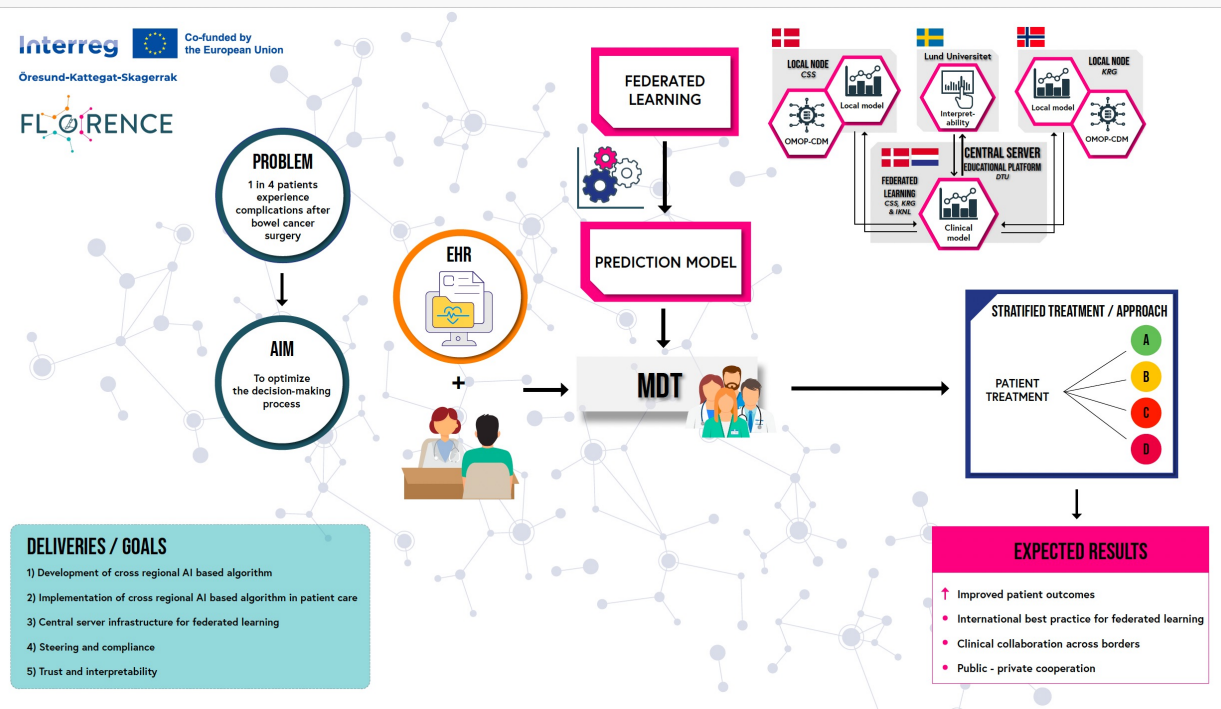
Developed and tested the OMOP Oncology Extension that supports granular representation of cancer diagnoses and treatments and clinically relevant disease and treatment episodes and outcomes. Integrated terminologies that provide comprehensive coverage of the oncology domain into the OMOP Standardized Vocabularies. Developed vocabulary-driven transformation from US Tumor Registries into the OMOP Common Data Model.

Relevance

The OMOP Oncology Module provides a platform for standardization of cancer data enabling the conduct of observational cancer studies and identifying patient cohorts in a distributed research network. Incorporated vocabularies create a foundation for manual or automated abstraction of cancer data to identify larger disease episodes and outcomes and enable automated transformation of the source data.



Federated Learning



JAMA Surgery | Original Investigation

Effect of Multimodal Prehabilitation on Reducing Postoperative Complications and Enhancing Functional Capacity Following Colorectal Cancer Surgery The PREHAB Randomized Clinical Trial

Charlotte Johanna Laura Molenaar, MD; Enrico Maria Minnella, MD, PhD; Miquel Coca-Martinez, MD, MSc; David Wouter Gerard ten Cate, MD; Maria Regis, PhD; Rashami Awasthi, MSc; Graciela Martínez-Palli, MD, PhD; Manuel López-Baamonde, MD; Raquel Sebio-García, MSc, PhD; Carlo Vitorio Feo, MD; Stefanus Johannes van Rooijen, MD, PhD; Jennifer Marijke Janneke Schreinemakers, MD, PhD; Rasmus Dahlin Bojesen, MD, PhD; Ismail Gögenur, MD, PhD; Edwin R. van den Heuvel, MSc, PhD; Francesco Carli, MD, MPH; Gerrit Dirk Slooter, MD, PhD; for the PREHAB Study Group

Key Points

Question Does a 4-week supervised multimodal prehabilitation program before elective resection of nonmetastasized colorectal cancer reduce postoperative complications and enhance functional recovery?

Findings In this multicenter, international randomized clinical trial that analyzed 251 adults, multimodal prehabilitation resulted in a significant reduction of severe and medical complications. The program also resulted in a statistically significant faster and better postoperative recovery.

Meaning Patients undergoing resection for nonmetastasized colorectal cancer may benefit from a 4-week multimodal prehabilitation program.