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OVERVIEW

BACKGROUND

Large-scale precision health initiatives, focused on translating genomics into clinical care and driving fundamental transformation in disease treatment and prevention, will soon generate the vast majority of human genomic data as they aim to sequence hundreds of thousands of individuals. The volume of data generated holds unprecedented promise for research and our understanding of human biology, but this will require the creation of a global ‘learning health system’ in which institutions and countries share tools, experience, knowledge, and—when appropriate—data across complex and variable healthcare systems around the world.

In order to strengthen international collaboration between national genomic initiatives, the Global Alliance for Genomics and Health (GA4GH), Australian Genomics (AGHA), and Genomics England (GEL) joined together for the seventh time to convene thought-leaders and domain experts from more than two dozen national and continent-wide genomics initiatives. With past meetings held in Vancouver, Canada (2016), London, UK (2017, 2019), Orlando, USA (2017), Basel, Switzerland (2018) and Toronto, Canada (2018), this year’s event took place virtually in response to the COVID-19 pandemic.

Under the leadership of Kathryn North (AGHA) and Mark Caulfield (GEL), these meetings aim to (i) identify potential opportunities to collaborate, (ii) share resources and expertise, and (iii) discover common needs across National Initiatives that GA4GH can incorporate into its repository of technical standards and policy frameworks. Efforts are currently shifting away from identification of collaboration opportunities and toward the active implementation of GA4GH standards as well as laying the foundation for data sharing pilot projects.

GENOMICS IN HEALTH IMPLEMENTATION FORUM (GHIF)

At the meeting, a formalized consortium of initiatives working to translate genomics into healthcare, titled the “Genomics in Health Implementation Forum (GHIF)”, was announced. The GHIF aims to empower knowledge exchange and collaboration among global initiatives as they pursue the common goal of advancing human health. The forum will help avoid both duplication of efforts across multiple initiatives as well as the collection of incompatible clinical genomic data and health information. Through global cooperation in data sharing and clinical implementation of genomics, we aim to support more accurate data interpretation, diagnosis, and low cost solutions across healthcare.
SESSION SUMMARIES

On March 23, 2020, initiatives from around the globe virtually convened to launch the first meeting of the formalized Genomics in Health Implementation Forum (GHIF). Attendees learned about the activity of pilot efforts launched to date and discussed future opportunities to advance global data sharing and human health.

INTRODUCTION TO THE GHIF/GOALS OF THE MEETING
Kathryn North (AGHA) and Mark Caulfield (GEL) kicked off the meeting by introducing the GHIF and its goals. Past GHIF meetings, previously known as “National Initiatives”, focused on sharing resources and identifying common challenges and opportunities for collaboration. Those efforts will continue as the group shifts towards actively implementing GA4GH standards and driving pilot projects, such as the efforts to harmonize consent forms and build a federated curation network. North highlighted the types of GHIF members, planned future meetings, and the ‘GHIF Toolkit’, where resources can be deposited and shared.

GA4GH STANDARDS OVERVIEW
Peter Goodhand (GA4GH) gave a brief overview of GA4GH and the technical standards that have been published to date, including Beacon, Service Info & Service Registry, Phenopackets, Variant Representation, Data Use Ontology, Passports & Authentication and Authorization Infrastructure (AAI), Workflow Execution Service, Tool Registry Service, Data Repository Service, htsget, refget and crypt4gh. More information on these standards can be found in the GA4GH toolkit.

OVERVIEW OF THE COMMUNITY
Lindsay Smith (GA4GH) summarized data collected from the GHIF Attendee Survey, which aimed to help everyone better understand the community represented in the GHIF: What are the common challenges that initiatives are facing? How much data are we collectively generating? Thirty-one initiatives spanning twenty-one countries registered for the GHIF. Of the 21 initiatives that completed the survey, the majority of initiatives are focused on infrastructure development and rare disease/cancer projects. Many initiatives are collecting whole genome and exome sequencing data, in addition to phenotypic, lifestyle and gene expression data. Common challenges included metadata harmonization, data access, and consent.
PILOT PROJECT INTRODUCTIONS/UPDATES

- **Gene Curation**: PanelApp: Ellen McDonagh (GEL), Zornitza Stark (AGHA), and Oliver Hofmann (AGHA) discussed global collaborative opportunities and localized GEL and AGHA implementations of PanelApp, a publicly-available, crowd-sourced knowledgebase that allows virtual gene panels related to human disorders to be created, stored, and queried.

- **Clinical Data**: Zornitza Stark (AGHA) provided an update on collaborative efforts to harmonize clinical data capture and exchange, specifically in the rare disease space. Highlights include a list of essential elements developed by GEL and AGHA that are necessary for genomic data analysis, and REDcap plug-in for pedigree data capture.

- **Public Engagement**: Your DNA, Your Say: Richard Milne (Wellcome Genome Campus) and Anna Middleton (Wellcome Genome CampusSanger Institute) presented results from Your DNA, Your Say, an international survey aimed at gathering public views on donating personal genetic and medical data for use by others. To date, 37,000+ individuals from 22 countries have completed the survey, which has been translated into 15 languages. The first meta-analysis between countries has been submitted for publication. The results of this study aim to inform policy recommendations for GA4GH (Website Link).

VARIANT CURATION AND FEDERATED VARIANT SHARING

Heidi Rehm (ClinGen/Matchmaker Exchange) and Augusto Rendon (GEL) discussed resources to support variant interpretation, curation, and sharing. Pilot project ideas for a federated platform for both variant and case level data exchange were introduced and interested groups are encouraged to reach out.

CONSENT

Kristina Kékesi-Lafrance (GA4GH) introduced existing efforts among GHIF members to collect genomic research consent clauses, which will be categorized and shared within a consent catalogue. Christine Patch (GEL) shared the evolution of consent as the UK 100,000 Genomes Project moved into NHS Medicine.

TOOLKIT AND NEXT STEPS

Kathryn North (AGHA) and Mark Caulfield (GEL) closed the meeting by introducing the vision for the GHIF Toolkit, a web resource for initiatives to deposit and view sharable material, and discussed details for future meetings.
ATTENDEE OVERVIEW

GEOGRAPHIC DISTRIBUTION OF GHIF ATTENDEES

AREA(S) OF FOCUS

- Rare Disease: 66.7%
- Cancer: 57.1%
- Complex Disease: 47.6%
- Health Population: 33.3%
- Infrastructure Development: 76.2%
- Social Sciences Research: 4.8%
- Epidemiology: 4.8%
- Clinical Trials: 4.8%
- In Silico Modeling: 4.8%
- Standards Development: 4.8%
- Indigenous Government & Representation: 4.8%
Initiatives may formally commit to being a GHIF member by completing the short form below on the GA4GH Website. Upon approval, initiative representatives will be added to GHIF member Google Group and given access to shared resources.

APPLY
PARTICIPATING INITIATIVES

1+MILLION GENOMES MEMBER STATE INITIATIVE
Europe
The 1+Million Genomes Member State Initiative aims to bring together more than 1 million genomes, along with phenotype and clinical information, by 2022 for the benefit of patients and citizens. Twenty-two European countries, many represented by their respective ministries, have signed a memorandum of understanding to: 1) Build a legal and ethical framework to enable cross-border sharing; 2) Develop a interoperable system to federate data and; 3) Establish standards for sequencing, phenotype and clinical data.

2025 FRENCH GENOMIC MEDICINE INITIATIVE
France
To ensure fair access to genomic medicine for all patients, France is implementing a national plan that aims to enhance the way to diagnose and treat patients by 2025. This initiative has been designed around the patient/physician partnership from the prescription of genome analysis to the medical report, and to introduce genome sequencing into the care pathway. Aviesan Alliance (French National Alliance for Life sciences and Health) was commissioned in April 2015 to propose and implement this national action plan. The first high-throughput sequencing platforms, SeqOIA in the Ile-de-France region and AURAGEN in the Auvergne Rhône-Alpes region, started to enroll their first patients in September 2019, and several clinical indications for access to genomic diagnosis have been validated by a working group led by the French National Authority for Health (HAS). Other recent achievements include the launch of pilot research projects in cancer, rare disease, common disease and population health, and the establishment of the Center of Reference, Innovation and Expertise (CRefIIX) to develop and harmonise best practices and standards.

ALL FOR ONE
Canada
All For One aims to improve the health and wellness of Canadians with serious genetic conditions by enabling access to a timely and accurate genomic-based diagnosis, laying the foundation for the implementation of precision health in clinics across Canada. Genome Canada has completed funding of five clinical sites with coverage of 7 out of 10 provinces and 90% of the population.
ARMENIAN GENOME PROJECT

Armenia

The Armenian Genome Project aims to resolve the reference genome of the Armenian population, turn Armenia into a regional hub for genomics research and infrastructure development, and bring personalized medicine into Armenia.

AUSTRALIAN GENOMICS HEALTH ALLIANCE (AGHA)

Australia

Australian Genomics is preparing Australia to embed genomic medicine into mainstream healthcare. This initiative is a federated system uniting 80 organizations, including clinical and diagnostic genetics services along with major research and academic institutions. Four main infrastructural programs - national diagnostic and research network, national approach to data federation and analysis, evaluation policy and ethics, and workforce and education - support clinical flagship projects in rare diseases, cancers, and reproductive carrier screening to serve as models for implementation and healthcare integration.

BIGMED

Norway

The BigMed project aims to address bottlenecks in the clinical implementation of precision medicine. It is the first major project in Norway of its kind and size to aspire to challenge established truths in the health service through the development of concrete demonstrators, products and guidelines, and to pave the way for subsequent initiatives and activities on the path to implementation of precision medicine. Based on four clinical areas—rare disease, sudden cardiac death, frost bites and colorectal cancer—the project develops solutions to identify barriers and to demonstrate how they can be overcome. The project covers a vast span of areas from quality in bioinformatic pipelines, data sharing for genomics and big data analysis (AI), clinical decision support, infrastructure and legal issues that need to be clarified or regulations that need changing. Recent achievements include sharing of variant classifications in Denmark via Variant Exchange, demonstrated working implementations of Matchmaker Exchange and the development of a variant interpretation working tool “ELLA” used in multiple hospitals.
BREAKING BARRIERS TO HEALTH DATA (WORLD ECONOMIC FORUM)
USA, UK, Australia, Canada
The Breaking Barriers to Health Data project aims to craft and test a scalable governance framework to support the effective and responsible use of federated data systems to advance rare disease diagnostic and treatment-related research globally. Recent achievements include the publication of a health economics framework written by leading health economists in the US, UK, Australia and Canada investigating the return-on-investment of implementing a federated data system and sharing genomic data across borders (found here).

BRAZILIAN INITIATIVE ON PRECISION MEDICINE (BIPMED)
Brazil
BIPMed aims to be the reference on the implementation of precision medicine in Brazil, being the catalytic element fostering collaboration between different stakeholders - scientists, physicians, health authorities and policy makers. This platform includes five Research Innovation and Dissemination Centers (RIDCs), and is the first of its kind in Latin America to offer public access to genomic and phenotypic data.

CANADIAN DISTRIBUTED INFRASTRUCTURE FOR GENOMICS (CANDIG)
Canada
CanDIG develops open source, standards-based, distributed, federated platforms that allow for querying and analyses of national scale genomics and human health data sets while data remains securely and privately controlled by its stewards. The CanDIG platform enables national-scale Canadian genomics projects such as the Terry Fox Canadian Comprehensive Cancer Centre Network, and PROFYLE, a precision pediatric oncology research effort. It actively participates in international work groups building standards for cloud workflow execution and data objects, dataset discovery, researcher identity and data use authorization ontologies and large-scale genomics analyses.

CANADIAN PARTNERSHIP FOR TOMORROW’S HEALTH (CANPATH)
Canada
CanPath – the Canadian Partnership for Tomorrow’s Health – aims to provide a national platform for population-level health research in Canada and globally. Six regional cohorts across nine provinces comprise CanPath’s pan-Canadian partnership to study the biology and behaviours of Canadians to learn more about the causes of chronic disease and cancer. To date, over 330k Canadians have volunteered to participate.
CLINGEN
International
ClinGen aims to build an authoritative central resource that defines the clinical relevance of genes and variants for use in precision medicine and research. The main goals of ClinGen are to support the deposition of genomic and health data into the public domain by all stakeholders, including patients, clinicians, laboratories, and researchers, develop methods and an informatics infrastructure to answer critical questions of the data (curation), and create a genomic knowledge base that makes this information available to the community for improved patient care.

COMMON INFRASTRUCTURE FOR COHORTS IN EUROPE, CANADA AND AFRICA (CINECA)
Europe, Canada, Africa
CINECA will enable population scale genomic and biomolecular data to be accessible across international borders, accelerating research and improving the health of individuals resident across continents. Recent achievements include the development of interoperable AAI between Europe and Canada (ELIXIR and CanDIG), establishment of Discovery Beacons and implementations of Data Use Ontology.

DANISH NATIONAL GENOME CENTER (NGC)
Denmark
The Danish National Genome Center (NGC) is a government agency and authority within the Danish Healthcare system. One of the National Genome Center’s primary objectives will be to map patient genomes and lay the foundation for the development of better diagnostics and more targeted treatments for patients. As a consequence, the center will have a highly specialized infrastructure with capacity for genome sequencing and a national genome database. Two specialized laboratory units, in the east and west of Denmark respectively, will be used to ensure full-country coverage.

FINNGEN
Finland
The FinnGen research project is a large-scale academic industrial collaboration aiming to create a dataset of ~500,000 Finns (~10% of the population) connected to electronic health records. The data created during the study will enable identification of genotype-phenotype correlations in the Finnish founder population and deepen our understanding of various diseases and their treatment. Recent achievements include the 2020 release of FinnGen Data Freeze 5 to FinnGen consortium partners, which includes genome-wide genotypes of 218 792 Finns and covers 2925 disease endpoints, with ≥ 80 cases.
**GABRIELLA MILLER KIDS FIRST DATA RESOURCE CENTER (DRC)**
*United States*

The Kids First Data Resource Center (DRC) is a collaborative pediatric research effort created to accelerate data-driven discoveries and the development of novel precision-based approaches for children diagnosed with cancer or a structural birth defect using large genomic datasets. The Kids First DRC is composed of integrated core teams that support development of leading-edge big data infrastructure and provide the necessary resources and tools to empower researchers and clinicians. Additionally, the Kids First DRC will connect patients, families, and foundations with the researchers studying specific disease areas. To date, the Data Resource Portal contains over 17k samples from over 12k participants.

**GENOME MEDICINE ALLIANCE (GEM) JAPAN**
*Japan*

GEM Japan is a project from the Japan Agency for Medical Research Development (AMED) which aspires to facilitate sharing of genomic and phenotypic information from completed and ongoing Japanese research efforts with the domestic and global communities. Recent achievements include adoption of and collaboration on several GA4GH standards to promote sharing of genomic and health-related data among domestic facilities, and sharing Japanese disease-related variants with global communities to contribute to global studies on discovering authentic genetic causes of disease.

**GENOMICS ENGLAND (GEL)**
*United Kingdom*

Genomics England was set up by the UK Department of Health and Social Care to sequence 100,000 genomes from NHS patients with a rare disease and their families, and patients with cancer. Thirteen Genomic Medicine Centres (GMCs) were built to identify and enroll participants, acquire consent, collect samples, and take responsibility for the interpretation and actionability of findings. In October 2018, the Health Secretary of the UK announced the expansion of the 100,000 Genomes Project to see 1 million whole genomes sequenced by the NHS and UK Biobank in five years.
GENOMIC MEDICINE SWEDEN (GMS)

Sweden

The strategic mission of Genomic Medicine Sweden (GMS) is to foster collaboration between healthcare providers, academia and industry in Sweden and realise precision medicine by effectively utilising the rapidly advancing sequencing technologies to provide the highest standards of genomic testing in routine clinical care throughout Sweden. GMS also acts as a unique resource and translational research hub for identifying disease-causing events that could pave the way for the development of new drugs, innovative healthcare solutions, and enhanced collaboration within the life science sector. Recent achievements include: 1) the establishment of seven genomic medicine centres across Sweden in all university healthcare regions; 2) development of an informatics infrastructure - National Genomic Platform - for computing, data storage and links to external third party resources; 3) linkages to Matchmaker Exchange and Beacon networks, and; 4) establishment of cancer WGS pilots and development of gene panels for myeloid, lymphoid malignancies and solid tumours in various stages of validation.

GENOMICS AOTEAROA

New Zealand

Genomics Aotearoa has established national collaborations in health, environment and primary production, and has funded projects across these three key research themes. The projects are underpinned by the development of a national genomics data repository and bioinformatics analytical platform, and by enabling and growing the skills and capability of researchers in New Zealand. The aim is to place Te Ao Māori at the centre of these activities, through research undertaken by and for Māori and embedding Māori management of indigenous genomics research practice and data. Recent achievements include the launch of a new project; Rakeiora: A pathfinder for genomic medicine in Aotearoa/New Zealand.

GERMAN HUMAN GENOME-PHENOME ARCHIVE (GHGA)

Germany

The German Human Genome-Phenome Archive (GHGA) will be embedded into the European infrastructure as a federated German node of the European Genome-Phenome Archive (EGA). As such, it will act as a national (but connected) infrastructure for secure and safe storage, access management, dissemination and analysis of human omics data under a coherent ethico-legal framework. GHGA will build on major existing German omics data providers and their IT infrastructure as well as the de.NBI/ELIXIR-DE infrastructure. Via direct connections to the data sources we will directly stream data onto the federated infrastructure. For all workflows, GHGA will adhere to and help to define new standards of the GA4GH. By going beyond a mere archival functionality, GHGA will enable and democratize access to even the largest population-scale datasets via secure, private cloud-based access.
**H3AFRICA**

*Africa (34 countries)*

The Human Heredity and Health in Africa (H3Africa) consortium aims to ensure access to relevant genomic technologies for African scientists, facilitate integration between genomic and clinical studies, facilitate training at all levels, and particularly in training research leaders and establish necessary research infrastructure. It facilitates fundamental research into diseases on the African continent while also developing infrastructure, resources, training, and ethical guidelines to support a sustainable African research enterprise – led by African scientists, for the African people. The initiative consists of 51 African projects that include population-based genomic studies of common, non-communicable disorders such as heart and renal disease, as well as communicable diseases such as tuberculosis. The consortium has over 250 publications and WGS and array data have been submitted to the EGA. An H3Africa member from Redeemers University was instrumental in controlling the Ebola outbreak in Nigeria and is involved in sequencing and analysis of Coronavirus cases in north and west Africa.

**HEALTH DATA RESEARCH UK**

*United Kingdom*

Health Data Research UK is uniting the United Kingdom’s health data to enable discoveries that improve people’s lives. By making health data available to researchers and innovators we can better understand diseases and find ways to prevent, treat and cure them. Recent achievements include leading the UK’s Data Science response to COVID-19, UK Health Data Alliance, Health Innovation Gateway.

**HEALTH-RI**

*Netherlands*

Health-RI is a public-private partnership of more than 70 organizations involved in health research and care. This partnership aims to build an integrated health data research infrastructure accessible for researchers, citizens and care providers and facilitate the optimal use of knowledge, tools, facilities, health data and samples to enable a learning healthcare system and accelerate sustainable and affordable personalized medicine and health. Health-RI follows three lines of action: 1) Collective action: optimizing the conditions for building and maintaining a national health data infrastructure; 2) Building a national health data infrastructure: fostering and facilitating initiatives and collaborations directed at developing health data infrastructure, and; 3) Providing mature services: supporting researchers and data managers by making infrastructure services, tools and data easy to locate, access and use.
**MATCHMAKER EXCHANGE**  
*International*

The Matchmaker Exchange is a federated platform using a standardized application programming interface and procedural conventions to match cases with the same candidate genes and enable evaluation of phenotype overlap to build evidence for candidate genes implicated in rare disease.

**NFDI4HEALTH - GERMAN NATIONAL RESEARCH DATA INFRASTRUCTURE FOR PERSONAL HEALTH DATA**  
*Germany*

The overarching aim of NFDI4Health is to create an infrastructure based on standards which thus enables harmonisation, is expandable and facilitates the retrieval and use of public health data, (dietary) exposure data as well as clinical trial data, facilitating structured combination and interoperability. The key objectives of NFDI4Health are to create new opportunities for data analysis in the interest of improving population health, including: (1) to enable findability of and access to structured health data from registries, administrative health databases, clinical trials, epidemiological studies and public health surveillance; (2) to implement a health data framework for centralised searching and accessing existing decentralised epidemiological/clinical data infrastructures, and; (3) to enhance data sharing, record linkage, harmonised data quality assessments, federated analyses of personal health data in compliance with privacy regulations and ethics principles.

**NIH ALL OF US RESEARCH PROGRAM**  
*United States*

The All of Us research program aims to collect genetic health data from 1 million volunteers to accelerate health research and medical breakthroughs and enable individualized prevention, treatment and care for all Americans. To date, 339k people have consented to participate in the National Institutes of Health’s program, and more than 265,000 people have completed the full protocol. Researchers will soon be able to access registered data, workspaces, a cohort builder tool, and an interactive notebook environment via a Researcher Workbench.

**NORDIC ALLIANCE FOR CLINICAL GENOMICS (NACG)**  
*Norway, Sweden, Denmark, Iceland, Finland*

The Nordic Alliance for Clinical Genomics aims to facilitate the responsible sharing of genomic data, bioinformatics tools, sequencing methods and best practices for interpretation of genomic data; enhance quality of genomic data and processes; develop demonstration projects that challenge perceived legal barriers that limit responsible and ethical sharing of genomic and health data; and build bridges between research and clinical communities, technologies and practices to foster innovation.
QATAR GENOME PROGRAMME (QGP)
Qatar
The Qatar Genome Programme (QGP) is a population-based project aiming to position Qatar among the pioneering countries in the implementation of precision medicine. The project is generating large databases combining whole genome sequencing and other omics data with the comprehensive phenotypic data collected at Qatar Biobank. QGP was launched by Qatar Foundation with a strategy based on seven building blocks: integrating with Qatar Biobank, utilizing local genomics and bioinformatics infrastructures, forging nationwide research partnerships, investing in local human capacity, drafting policies and regulations, and building a national genome data network and integrating genomics into the clinical settings. To date, over 19,000 whole genomes have been sequenced.

SINGAPORE NATIONAL PRECISION MEDICINE PROGRAMME (SG NPM)
Singapore
The Singapore National Precision Medicine programme (SG NPM) aims to create a population-scale data bank containing longitudinal genetic, clinical, and lifestyle data of up to 1 million Singaporeans to improve patient outcomes, mitigate rising healthcare costs, and capture economic value. The 10 year programme is divided into three phases. Phase I was established to demonstrate the feasibility of “at-scale” data generation, analytics, and linkage, and to generate learnings to advise the design of subsequent phases. A major Phase I deliverable is a whole-genome database of 10,000 healthy Singaporeans. Drawn from existing cohorts, the SG10K_Health cohort will be used by the medical community to prioritise disease-causing mutations. Phase II aims to capture genetic and phenotypic diversity across 100,000 healthy Singaporeans. It will generate Asian-specific genotype/phenotype hypotheses relevant to health and disease, establish platforms for national-scale clinical/lifestyle data collection and integration, and inform the design for cost-affordable genotyping arrays for Phase III scale-up. Phase III will scale-up the genetic and phenotypic collection of data of up to 1,000,000 Singaporeans, and extend the data capture platform to include social and environmental data. Phase III data will be used to statistically validate hypotheses generated in Phase II, which will form the basis of long-term public health and policy decisions.
COLLABORATIVE STANDARDS ORGANIZATIONS

INTERNATIONAL ORGANIZATION FOR STANDARDIZATION (ISO)

International

The International Organization for Standardization (ISO) is an independent, non-governmental organization, the members of which are the standards organizations of the 164 member countries. It develops and promotes worldwide proprietary, industrial, and commercial standards. Two specific ISO committees collaborate with GA4GH and GHIF efforts: ISO/TC 276/WG5: Data Processing and Integration and ISO/TC 215/SC1: Genomics Informatics.

- **ISO/TC 276/WG 5**: Data Processing and Integration aims to develop standards for traceable, searchable, and interoperable data together with integrated data processing for biotechnology/life sciences. The main foci are: definition of data and model formats and their interfaces; definition of metadata and relations of data and models, and; quality management of processed data and models.

- **ISO/TC 215/SC1**: Genomics Informatics aims to standardize computable data, information, and knowledge, including their representation and metadata, for the application of omics, including but not limited to genomics, phenomics and proteomics to support human health and clinical research.

EU-STANDS4PM

Europe

EU-STANDS4PM is a Coordinating and Support Action funded under the Horizon2020 framework programme of the European Commission. At the core of this project is a pan-European expert forum and network that combines extensive experience from its sixteen partners, including H2020 collaborative research projects, normative and regulatory agencies, large European infrastructures, Industry as well as ethical and legal expertise from eight European countries. A central goal is to develop harmonised transnational standards, recommendations and guidelines that allow a broad application of predictive in silico methodologies in personalised medicine across Europe. Recent activities include development of a draft for a harmonized data access agreement for data used in in silico modeling in personalized medicine, and a legal and ethical review of in silico modelling submitted to the European Commission (EC). EU-STANDS4PM is actively involved in the drafting of standards, especially in ISO/TC 276 Biotechnology and ISO/TC 215 Health Informatics, but also collaborates with scientific and clinical standardization initiatives and committees.
Health Level Seven International (HL7) is a non-profit, ANSI-accredited standards development organization dedicated to providing standards and solutions that empower global health data interoperability. Specifically, they are developing a set of international standards for transfer of clinical and administrative data between software applications used by various healthcare providers to support clinical practice and the management, delivery and evaluation of health services. HL7 is supported by more than 1,600 members from over 50 countries, including 500+ corporate members representing healthcare providers, government stakeholders, payers, pharmaceutical companies, vendors/suppliers, and consulting firms.