HDR UK::GA4GH Strategic Partnership

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Overview

This document outlines the rationale and implementation of a Strategic Partnership between Health Data Research UK (HDR UK) and the Global Alliance for Genomics and Health (GA4GH). This Strategic Partnership builds on significant existing collaboration between the two organisations. This document describes the current and future complementary activities carried out by both organisations to ensure responsible and trustworthy data sharing in the UK and beyond, including a larger framework for cooperation.

Health Data Research UK (HDR UK) is the national institute for data science in health. The mission is to unite the UK's health data to enable discoveries that improve people's lives. The 20-year vision is for large scale data and advanced analytics to benefit every patient interaction, clinical trial, biomedical discovery and enhance public health. HDR UK works with a wide range of health data from the NHS, universities, research institutes and charities, private companies and from wearable and mobile technologies. The institute has also recently convened international programmes, recognising that challenges to human health are increasing globally. By making health data available to researchers HDR UK aims to develop a better understanding of these diseases and ways to prevent, treat and cure them.

HDR UK convenes the UK Health Data Research Alliance which brings together over 100 data custodians, trusted research providers and other key institutes across the UK. This group develops and co-ordinates the adoption of tools, techniques, conventions, technologies, designs, and consistent approaches that enable the use of health data in a trustworthy and ethical way for research and innovation. Standardisation of information governance and data

access models underpinned by the five-safes principles, drives down barriers for researchers and promotes consistency across the landscape. This is happening in the UK and beginning to be adopted more internationally. A GA4GH partnership could potentially help accelerate this work.

GA4GH unites an international community dedicated to advancing human health through genomic data interoperability and sharing. GA4GH builds technical standards and policy frameworks to expand responsible, voluntary, and secure use of genomic and other related health data. GA4GH consists of more than 500 leading organisational members active in healthcare, patient advocacy, research, ethics, government, life science, and information technology. Together, this community is working to turn the promise of genomic medicine into routine practice by creating privacy-protective methods for sharing vital knowledge that could benefit all of us. To achieve this vision, the GA4GH community develops free, open-source products that make it simple and safe to request, access, and study data. All GA4GH work builds on the *Framework for responsible sharing of genomic and health-related data*, guided by the Universal Declaration of Human Rights.

Mission

Through this strategic partnership, GA4GH and HDR UK aim to work collaboratively to expand one another's scope and impact in the standards and health data landscapes, respectively.

GA4GH links HDR UK to the standards used by the genomics community and offers HDR UK the opportunity to expand its existing open standards work and collaborate in the broader health data space via GA4GH's extensive network. HDR UK provides GA4GH with a key connection to the health data landscape, an area which has been underrepresented within the GA4GH community to date, but which is critical for the organisation's success.

Both partners also plan to expand collaborations with international and global partners as part of these activities, to learn from and promote adoption of health data related standards around the world.

What are Strategic Partnerships?

As described in the GA4GH Connect: 2022 Strategic Refresh document, Strategic Partnerships are an organisational framework that helps align two or more groups to increase the benefit of their collective participation.

The exact design of a strategic partnership can be specific to the partners as long as the framework is open, fair, and regular.

Success criteria

Criteria for measuring the success and benefits of this Partnership include:

- Increased engagement of HDR UK individuals across GA4GH Work Streams
- Onboarding of new initiatives instigated by HDR UK into GA4GH
- Alignment of GA4GH and HDR UK activities in key areas of focus, such as data standardisation and technical solutions streamlining and supporting trustworthy data use

Current Activities

To-date, HDR UK has been involved in a number of GA4GH workstreams, including infectious diseases, ethical preparedness for pandemics and epidemics, and metadata standards, and has considered use of beacons and federated queries.

Scientific Need

The imperative for genomic data in healthcare is underscored by the necessity for large cohorts, potentially encompassing millions of participants, to unravel the genetic and molecular intricacies of diseases. These cohorts serve as the foundation for tailoring personalised treatments. Worldwide, over 200 genomic data initiatives are in progress to facilitate the creation of such datasets. Alongside this landscape, HDR UK is the UK institute for health data science, which is uniting the UK's health data to enable discoveries that improve people's lives. The HDR UK::GA4GH Strategic Partnership will strengthen GA4GH's presence in the international health data community and help advance its mission to link genomic and health data to advance research and medicine.

Realising the potential of health-related datasets poses a significant challenge, requiring substantial investments in national and international infrastructure. The complexity and scale of this endeavour transcend the capacity and jurisdiction of any single organisation. International collaboration becomes paramount to establish recognized, secure, standardised, documented, and interoperable services. Building upon existing collaborative efforts between HDR UK and GA4GH, the HDR UK::GA4GH Strategic Partnership will spearhead the development and implementation of the GA4GH suite of interoperable standards and policy frameworks within the UK health data landscape and promote the adoption of UK best practices within and garner feedback from a broader international context. This concerted effort aims to surmount technical and regulatory obstacles hindering the responsible sharing of health related data.

Standards that are of particular interest to HDR UK include GA4GH Beacons, federated queries & federated analysis, researcher passports, metadata standards for health and health related data, cohort discovery, and trusted research environments (e.g. making outputs of DARE UK projects such as SATRE a global concept). HDR UK has already implemented several GA4GH standards and continues to actively support, implement, and deploy open standards in collaboration with GA4GH.

The Strategic Partnership will also aim to bring HDR UK's international and global south partners and collaborators to GA4GH projects in greater numbers, a critical effort in ensuring GA4GH standards are fit for purpose for the international community.

The HDR UK::GA4GH Strategic Partnership is committed to providing technical solutions that support trustworthy use of health data and align with data providers' constraints and researchers' requirements within a federated ecosystem of implementers.

Operational Need

The HDR UK::GA4GH Strategic Partnership (SP) aims to expand HDR UK and GA4GH influence on health data and health-related standards and technologies across the international setting. Through the SP, the two parties intend to support HDR UK participation in the development of GA4GH standards, and dissemination of those standards across its community, both within the UK, but also on an international basis via global collaborations and initiatives.

GA4GH recognizes that it has limited capacity to solicit community involvement through Driver Project relationships alone, and is currently managing collaborations with 28 disparate genomic data projects with varying levels of complexity. As GA4GH continues to mature as a global standards organisation, it will need to develop a mechanism to engage the international health data community at a higher level. A Strategic Partnership with HDR UK will help achieve this by connecting GA4GH to the network of HDR UK initiatives through a single touch point.

How it works in practice

HDR UK and GA4GH intend to collaborate on a number of areas, some already in flight, some new through either participating in existing Work Streams and other activities or initiating new ones. HDR UK and GA4GH will hold strategic meetings every 6 months to align and drive progress across the partnership. GA4GH and HDR UK will also strive to send delegates to one another's meetings where appropriate.

Roles and Responsibilities

HDR UK Strategic Partnership Champion: GA4GH Steering Committee representative for overall strategic direction for HDR UK. Brings perspective from HDR UK as well as works with leads across HDR UK platforms and communities. Ensures external visibility and relations. Votes at Steering Committee*.

HDR UK Strategic Partnership Technical Champion: GA4GH Steering Committee representative for overall GA4GH technical direction for HDR UK. Aligns and works with HDR UK initiatives.

GA4GH Steering Committee meetings

The Partnership Champion and Partnership Technical Champion will be invited by GA4GH to attend GA4GH Steering Committee meetings (see appendix). The Strategic Partnership will be allotted one vote on SC decisions.

Voting representatives need to take on board opinions from HDR UK observers and have live contact with the observers on the call to ensure a consensus from HDR UK.

Strategic Partnership Meetings

The SP Champion and Technical Champion will organise two **HDR UK::GA4GH strategic virtual meetings** per year to discuss issues relating to the SP. Those named in Appendix 1 are expected to participate in these meetings, though additional delegates are also welcome to attend. These meetings shall focus on success criteria, new potential projects, and the delivery of coordinated infrastructure demonstrations. GA4GH will participate and provide input into key HDR UK partnership meetings, steering committees and alliances.

Appendix 1:

HDR UK individual participation on GA4GH product teams

Name	Title	SP Role	Product Teams
Emily Jefferson	CTO	SP Champion	
Andy Yates	Chief solutions architect	SP Technical Champion	Beacons & federated queries + meta data
Andrew Morris	Director Health Data Research UK		
Edel McNamara	Information Governance lead		Data Security, Regulatory & Ethics
Anne Wozencraft	Director of Global Programmes		Regulatory & Ethics, Global
Sangya Pundir	Product owner, Cohort Discovery		Cohort discovery
Wendy Bacon	Product Owner, Safe People Registry		Researcher Passports

Appendix 2:

GA4GH key contacts for HDR UK Engagement

Name	Title	SP Role	Product Teams
Peter Goodhand	CEO		
Sasha Siegel	Chief Standards Officer		
Angela Page	Director, Strategy & Engagement	Coordinator	
Jimmy Payyappilly	Technical Lead		
Beatrice Amos	Work Stream Manager		Clinical & Phenotypic Data Capture, Discovery, Genomic Knowledge Standards
Reggan Thomas	Work Stream Manager		Large Scale Genomics, Cloud
Jessica Seegobin	Work Stream Manager		Regulatory & Ethics, Data Security
Amreen Mohamed	Work Stream Coordinator		Data Use & Researcher Identities