

The next phase of the UK Health Data Research Alliance – A Summary of responses and feedback to the Alliance’s future governance and ways of working consultation

Background

The UK Health Data Research Alliance was established in February 2019 as an independent alliance of health data providers, custodians and curators dedicated to improving human health by maximising the potential of data to accelerate progress in biomedicine, health and care. It is made up by partner organisations (members), each of which brings experience in domains relevant to its mission along with an outstanding record of and commitment to serving the public good. It is a non-for profit association and to date funded by UKRI through the Innovate UK Industrial Strategy Challenge Fund as part of the Digital innovation Hubs programme.

Alliance-related activities have also received funding through the UKRI COVID-19 Data & Connectivity National Core Study (NCS), HDR UK core funding and UKRI/MRC Capital Funding. The ISCF and NCS funding runs until March 2023.

The Alliance ‘constitution’ is set out in the [Letter of Intent](#) signed by all organisations joining the Alliance. The Letter of intent has drawn heavily on analogous collaborations and alliances, in particular the Global Alliance for Genomics and Health (GA4GH). It was updated periodically between formation of the Alliance in February 2019 and March 2020. Changes made reflected the addition of the Principles for Participation that were put in place for the launch of the Industrial Strategy Challenge Fund (ISCF) Digital Innovation Hub (DIH) programme prospectus in May 2019 and the development of the Health Data Research [Innovation Gateway](#).

The need to review and update

As the ISCF funding comes to an end, we have been reviewing the current Alliance governance and Letter of Intent and have consulted a number of Alliance members and partner organisations to seek feedback and input into the next phase of the Alliance.

From April 2023, the Alliance secretariat and convening activities has been included in the HDR UK core funding as an integral part of its second quinquennium plans for research data infrastructure and services. These plans cover four thematic areas (or pillars):

- a. Trust and Transparency
- b. Technology services ecosystem
- c. Useable Data
- d. Capacity Building

This suggests that there is an opportunity to ensure alignment of Alliance activity with HDR UK’s developments in the research data infrastructure and services work and ensure close collaboration between Alliance members and partners and HDR UK colleagues.

The growth of the Alliance, from ten founding members to over 70 today, and the ‘evolution’ of the health data ecosystem, as a result of the pandemic and the UK leaving the EU, have also contributed to our decision to revisit the Alliance governance and propose new ways of working.

What Alliance members told us

This report provides a summary of main themes and suggestions highlighted by Alliance members and partners during a consultation period between July and December 2022.

Alliance members and colleagues were asked for input on updating the governance model to reflect the growth of the Alliance and changes in the ecosystem to ensure it is fit for purpose for the next phase of the Alliance's development.

The insights summarised below are the result of discussions during workshops, focus groups, individual interviews and responses to a consultation questionnaire, and directly informed the new governance model and proposed way forward for the Alliance to be signed off in January 2023 and effective from April 2023.

A total of 25 individuals responded to the survey, 7 people were interviewed and more over 30 participants attended the workshops.

1. Extending membership beyond data custodians

It was proposed that the Alliance should continue to be a member-led alliance of health data providers, custodians and curators. Members were asked if they agreed that membership should also be opened up to complementary 'non-data custodians' groups and organisations to increase coherence, reduce duplication and extend influence and reach. These groups could include decision makers and regulatory bodies such as National Data Guardian, Health Research Authority, MRC Regulatory Support Centre, research funding organisations, Information Commissioner's Office etc.

The majority of survey respondents (88%) agreed with the proposed approach and indicated that non-data custodians should be invited to join the Alliance.

'Opening up membership to complementary groups will ensure all parts of 'the system' are working collaboratively and in alignment'

'This will broaden our reach and publicity. It will also help with the Infrastructure Services development'

'This is a very good idea as the bodies suggested are heavily integrated to the data access routes or provide leadership and influence in this space'

2. Engagement beyond non for profit and publicly funded bodies

To date, commercial organisations have not been able to join the Alliance as members. They have been able to engage with some Alliance activities through forming part of member collaborations (e.g., Health data research hubs, AI Centres of Excellence) or through contributing to working groups and/or open consultations. This approach was considered appropriate for the first phase of the Alliance following discussions with founding Alliance members.

Given the importance of life science and technology companies to enabling and implementing discoveries that improve people's lives, as well as improving research productivity, their involvement in the development of the research data infrastructure and services and trustworthy use of data is critical.

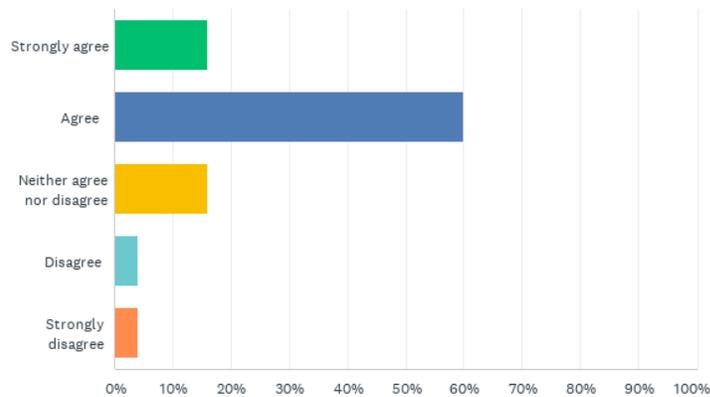
Opening up Alliance membership could improve opportunities for collaboration and accelerate progress. However, consideration needs to be given to public and patient views on new arrangements, as well as those of existing Alliance members.

Respondents were asked whether membership should be extended beyond non for profit and publicly funded body. This option was received with mixed views. While many indicated that engagement with for profit organisations is important and could be helpful, perhaps via an open forum or a working group, Alliance membership was considered not appropriate at this stage. Some respondents commented that caution should be taken with regards to potential invested interests from commercial partners, whilst others were supportive of a diverse Alliance which works collaboratively for the benefit of all, suggesting that there could be ground rules that can be signed up to so that fairness and transparency are maintained.

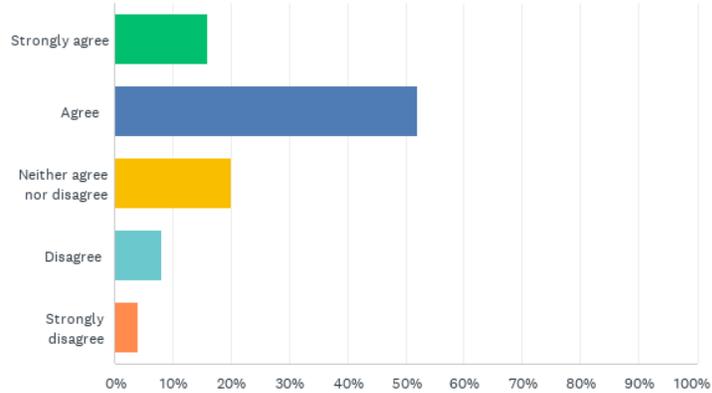
While recognising the advantages of engaging with for profit infrastructure data providers, data custodians and data users, and the opportunity to learn from a diverse pool of organisations, potential challenges were highlighted, such as the need to have an application process for membership, including declaration of interests and the need for transparency throughout as well as patient involvement in decision making. A suggestion was to consider working with Trade Associations, such as the Association of the British Pharmaceutical Industry (ABPI) as they have similar interests.

A summary of the survey responses on this topic is provided in the graphs below.

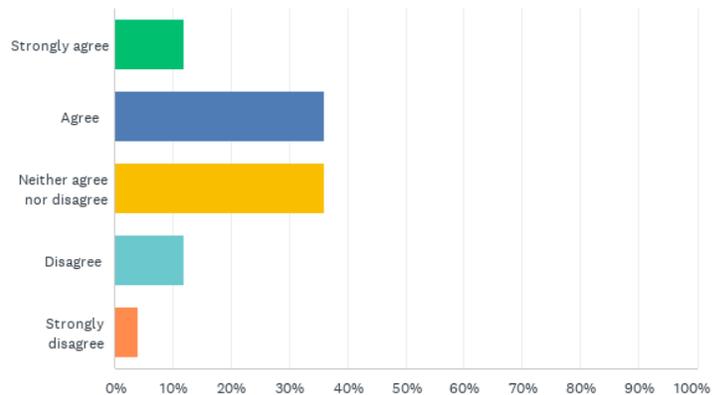
Q8 Do you agree that the Alliance should engage more with private data custodians?



Q9 Do you agree that the Alliance should engage more with private providers of infrastructure and services?



Q10 Do you agree that the Alliance should engage more with private users of data?



3. The Alliance Board Model

The Alliance Board currently includes senior representatives from all member organisations (74 to date) and meets on a quarterly basis to share developments across the landscape, discuss best practice in data use and evaluate outputs produced by current Alliance working groups. It is proposed to move to a representative model in the form of an Alliance Executive Committee.

The role of a representative Alliance Executive Committee would be to inform strategy and development of the health data research infrastructure and services and shape improvements in **Technology Services ecosystems, Trust and Transparency, Data Usability** and **Capacity Building**.

It is proposed that the Committee will meet to discuss strategic direction for the Alliance and inform prioritisation of activities around development of health data infrastructure.

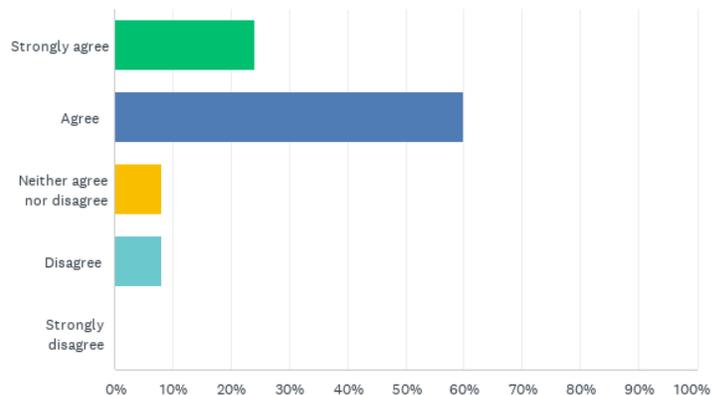
It is also proposed that we will hold annual Alliance Plenary meetings to bring together the Alliance community and showcase work of Alliance members, outputs, and developments in the UK health data landscape.

Working groups and special interest groups will occur throughout the year to drive the development of tools, standards and recommendations.

When asked whether they agreed with the approach proposed, the majority of respondents welcomed the proposal and indicated that a smaller, representative steering committee would be helpful to provide strategic input into relevant Alliance initiatives, to inform prioritisation and guide delivery of activity. However, many members recognised the value of current quarterly Board meetings, and strongly suggested maintaining these for information sharing and networking.

Many of the individuals interviewed and the survey respondents noted that while a smaller representative committee is appropriate to determine focus and drive delivery, it is crucial to ensure a route for members to have their voices heard and a mechanism to bring relevant topics for discussion to the Executive Committee. If governed in a way that all members are given opportunity to input and take part in various sub-committee, special interest groups or working group, the addition of an Alliance Executive Committee is welcome.

Q13 Do you agree with moving to a smaller, representative Alliance Board and associated annual plenary?

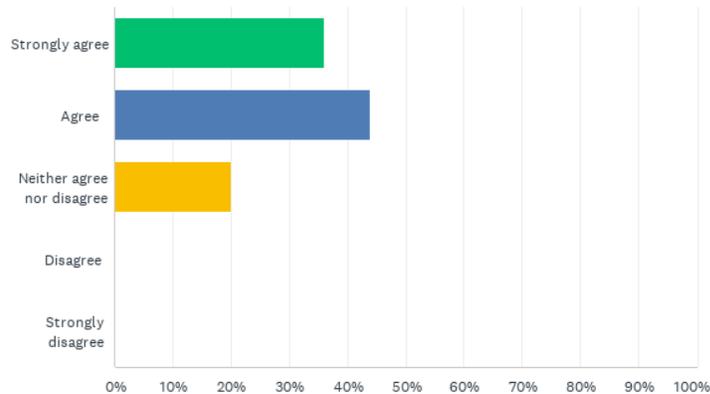


Alliance emerging ways of working

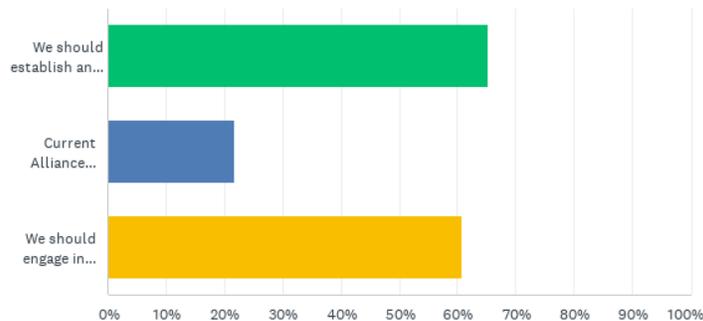
It is proposed that the Alliance will continue to convene and grow communities of interest that reach across the UK and beyond, aligned with Alliance principles for participation and shared purpose. These communities of interest will continue to shape, agree and promote adoption of standards and best practices. It is suggested that Alliance activities will be grouped, as far as possible, under **Technology Services ecosystems; Trust and Transparency; Useable Data;** and **Capacity Building** to maximise alignment with HDR UK Infrastructure and Services pillars.

The majority of survey respondents (80%) and interviewed individuals agreed that alignment between Alliance activities and HDR UK's strategy on research data infrastructure services is needed.

Q16 Do you agree with aligning Alliance activities with the HDR UK Infrastructure & Services pillars? Yes



Q19 How do you suggest the Alliance should engage with international organisations sharing similar goals?



When asked about structure and frequency of Board and community meetings, many respondents indicated that current quarterly Board meetings are valuable and should be continued. One of the main strengths of the Alliance is the ability to convene a diverse pool of stakeholders and partners who share commitment to improve the way data is used. There are not many fora bringing the health data community around this aim and providing such opportunity for networking and keeping up to date with developments in the health data landscape. There was strong support towards continuing information sharing community meetings in addition to the development of a smaller Executive Committee.

The next five years

In the next five years, the ambition of the Alliance is to become an internationally recognised and influential collaboration of health and care organisations united to establish and implement best practices, tools and standards for health data science at scale to deliver public benefit.

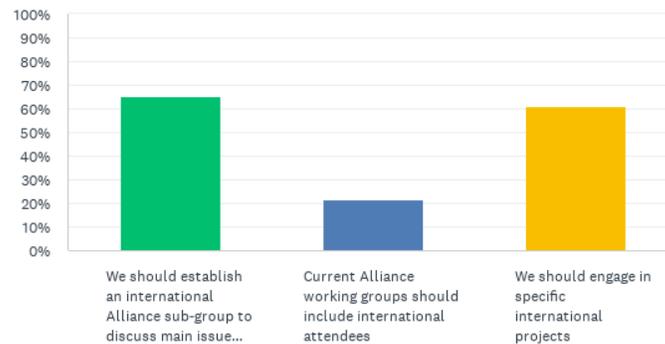
The Alliance will focus on two main priorities:

- improvement of information governance data access processes and increase in trust and transparency
- adoption of commonly recognised international standards for data, tools and processes to ensure effective use of high-quality data

To ensure relevance of the Alliance within the health data landscape it is also suggested that stronger links with international players should be made. Alliance members were asked how best to achieve this and the options chosen are displayed below.

65% think we should establish an international Alliance sub-group to discuss main issues around use of health data for research and innovation. 21% think Current Alliance working groups should include international attendees and 60% think we should engage in specific international projects.

Q19 How do you suggest the Alliance should engage with international organisations sharing similar goals?



Next steps

The results of this consultation will directly inform the next phase of the Alliance. Some key changes to the current Alliance governance and ways of working will be presented at the next Alliance Board meeting on 26 January 2023 with the aim to implement changes in April 2023.