



Terms of Reference

UK Health Data Research Alliance Executive Committee



Contents

Terms of Reference	1
Document control.....	3
UK Health Data Research Alliance	4
Alliance Executive Committee	5

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Document control

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Dec 22 – Issue 1	All	Collated Alliance Executive Committee and Alliance Council Terms of Reference into a single document
Apr 23–Issue 2		Alliance Executive Committee

Classification	Definition
Public	Access is unrestricted; document may be shared publicly e.g. made available via the website.
Restricted	Access is restricted to a defined group and must not be shared beyond those identified

UK Health Data Research Alliance

Introduction

No single organisation collects and holds all the information required to address every knotty health and well-being issue facing society. Timely access to data across organisations for research and innovation requires expertise, trusted governance, and interoperability (the ability to work across institutions with no additional effort) between organisations that control data. The UK Health Data Research Alliance has been established as a forum to develop a portfolio of tools, processes, capabilities and information governance approaches that will help organisations to unlock data-driven research and innovation.

The Alliance's objective is to **accelerate progress** in medicine and health by **encouraging better access** to structured and unstructured clinical, administrative, genomic and other molecular data in a **trustworthy and ethical** way for the purposes of **research and innovation**.

The UK Health Data Research Alliance Council (former Alliance Board) and the Alliance Executive Committee have been established to provide:

- Action focused governance and leadership.
- Transparent and efficient decision making.
- Priorities for growth.
- Commitment to public engagement.

An Alliance Secretariat resourced by HDR UK will support the Alliance Executive Committee and the Alliance Council and manage the core operational decisions of the Alliance.

Secretariat

Director of Infrastructure & Services, Head of Alliance Strategy & Engagement, Alliance Delivery Manager, Project Manager, Alliance Programme officers.

Alliance Executive Committee

Purpose and remit

The Alliance Executive Committee's purpose is to provide strategic leadership of the Alliance and ensuring its activities are in alignment with strategies across all areas of the health data ecosystem.

It is responsible to the Alliance membership, represented through the Alliance Council. Its remit is:

- To uphold the spirit of the Letter of Intent and associated Principles for Participation, and to agree the actions required if members do not adhere to the Alliance principles and ways of working.
- To guide the growth and development of the Alliance, including making recommendations on the criteria to identify and prioritise potential Alliance members and defining measures of success and periodically review progress towards agreed goals.
- To support co-ordination across the major health data infrastructure investments across the UK so that the Alliance contributes to the whole being greater than the sum of the parts, and unnecessary duplication is avoided.
- To develop and evaluate the Alliance's annual programme of work.
To advise on the priorities of infrastructure services programmes, based on community input and assessment of the health data landscape. To prioritise community engagement activities as well as development of workstreams, special interest groups, delivery sub-groups in alignment with HDR UK infrastructure programmes and other ecosystem developments.
- To receive comments, advice and recommendations from advisory boards and reference groups associated with the Alliance.
- To shape the Alliance's communications strategy, including public and patient involvement and engagement.
- To shape and agree Alliance Council meeting topics and agendas.

Composition and running of the Committee

Membership

The Committee shall be made up of [up to 12] individuals representing the diversity of Alliance member organisations and strategic partners e.g. :

- Representatives from relevant Government Departments and/or national NHS bodies and/or Public Health agencies from each of the four nations of the United Kingdom
- NHS Trusts (possibly through NHS Confederation)
- NIHR Biomedical Research Centres (nominated lead)
- Medical Research Charities (possibly through Association of Medical Research Charities)
- Industry Trade associations
- Providers of Data Infrastructure and Services (e.g., Hubs and Data Science Centres/Centres of Excellence, Custodians of large-scale research cohorts, CPRD)
- Academic centres
- Research funders

Plus members of the Alliance Secretariat.

Others may be invited by Committee members (or in their absence, their deputy) to attend all or part of any meeting.

Membership is reviewed annually.

Chair

The HDR UK Director shall act as Chair of the Alliance Executive Committee, as per current approach. In their absence, their deputy shall act as Chair. It is proposed that Chair appointment is reviewed every 12 months.

Secretary

The Head of Alliance Strategy & Engagement or their nominee shall act as the secretary of the Committee.

Quorum

The quorum necessary for the transaction of business shall be [6] members of whom at least one must be either the Alliance Executive Committee Chair or their deputy. A duly convened meeting of the Committee at which a quorum is present shall be competent to exercise all or any of the authorities, powers and discretions vested in, or exercisable, by the Committee.

Frequency

The Committee shall meet on a quarterly basis for 2 hours through Zoom-enabled meetings and as necessary to despatch the business effectively.

Notice of meetings

Meetings of the Committee, other than those regularly scheduled as above, shall be summoned by the secretary of the Committee at the request of the Alliance Executive Committee Chair.

Unless otherwise agreed, notice of each meeting confirming the venue, time and date together with an agenda of items to be discussed and supporting papers, shall be forwarded to each member of the Committee and any other person required to attend, no later than [2] working days before the date of the meeting.

Record keeping

For efficiency, full minutes will not be captured and the proceedings and resolutions of all meetings of the Committee will be recorded in the form of notes and actions points. These will include the names of those present and in attendance.

Draft notes and actions points shall be circulated promptly to all members of the Committee and, once agreed, to all members of the Alliance Council. These will also be published on the Alliance website.

Reporting responsibilities

The Alliance Executive Committee Chair shall report to the Alliance Council on the proceedings of the Committee since the previous Council meeting.

Commencement

1. These terms of reference shall commence from the date of approval by the Alliance Executive Committee once formed.
2. These terms of reference will be reviewed no later than two years from the date of approval of the Board.

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