Health Data Research UK Public Advisory Board
Terms of Reference

Updated January 2022

INTRODUCTION

The Public Advisory Board is vital in helping position Health Data Research UK as a leading international institute for health data research. We can only achieve our vision and strategy if patients, the public, practitioners and key stakeholders have trust and confidence in the safe and secure access and use of health data for research and innovation.

The Public Advisory Board is in place within HDR UK's Governance structure to provide strategic advice to HDR UK, with a particular focus on how we can work together to:
- Encourage and enable effective health data science by involving patients and the public
- Demonstrate trustworthiness and build public confidence in Health Data Research UK's work and the safe and secure access and use of health data in research
- Build public understanding of the safe and secure access and use of health data in research
- Ensure people feel confident in contributing their data for research and data linkage

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The Public Advisory Board provides guidance on strategy to HDR UK with the aim of ensuring that our work is driven by and delivered with patients and the public, for patient and public benefit. In particular, strategic advice will be focused on those areas of data access and use where we know there are challenging and complex questions which has the potential to impact public trust.

The Public Advisory Board will achieve this by:
- Providing input to and influencing the development of HDR UK's vision, ambitions and strategy and the annual business planning process (including any relevant review processes e.g., Establishment Review, Quinquennium review etc.)
- Providing strategic advice and guidance on the start-up/development of HDR UK's programmes to ensure they are planned with appropriate patient and public involvement and guided by the patient and public voice.
- Identifying opportunities for HDR UK to contribute to national debate and policy on public involvement in health data research
- Helping shape HDR UK's public and patient involvement and engagement (PPIE) strategy and approach and providing advice on how the strategy is delivered.
- Where there is an unmet need, provide support and advice to different areas of the organisation to ensure that PPIE is embedded from the beginning.
- Providing a patient and/or public perspective at meetings, workshops, events and panels – both internally and externally to HDR UK.
- Providing constructive challenge where patients and the public have not been sufficiently involved or engaged and working with us to find ways to meaningfully involve patients and the public moving forward.

- Advising on HDR UK's public and patient involvement and engagement measures of success, periodically reviewing progress towards goals.

- Developing an annual work plan for the Board that enables members to contribute expertise and detailed input to specific areas of work – this work plan should highlight strategic areas of focus to address challenging and complex questions that have the potential to create risk to public trust.
    - This includes, but is not limited to, advising how best to carry out meaningful involvement and engagement activities within each area of work. The work plan is developed with input from the Board with guidance from HDR UK staff.
- Contributing to a regular update to the Executive Committee which includes but is not limited to, pre-identified key areas of focus, recommendations on HDR UK's strategic approach, areas of HDR UK's work that may have a potential effect on public trust and ways to better demonstrates trustworthiness.

- Support the PPIE team in developing our narrative to help to articulate the benefits of health data research to a public audience and, where reasonable, for members to act as advocates for HDR UK.
- Advising on approaches to build public understanding of the benefits of using health data in research.
- Contributing to HDR UK's publications, website and other communications channels to ensure that information is clear and concise for a public audience.
- Encouraging openness and transparency in engaging with patients and the public, and high standards of involvement of patients and the public.

- Fostering HDR UK's values of transparency, optimism, respect, courage and humility (TORCH), which guide how the Advisory Board works with HDR UK, its partners and stakeholders including patients and the public.

MEMBERSHIP AND MODE OF WORKING
- Members of the Board provide a perspective of patients, carers and the public. Members bring a range of perspectives, and are not required to be pro-access for health data.
- Members may be patients, carers and/or may have experience of working in public engagement or involvement.
- Members hold their post for an **initial period of 12 months**, with the potential for extension or **renewal for a further two years**. This allows membership to change to bring in new or additional perspectives.
- The **Chair and Deputy Chair hold their post for two years**.
- Members may bring their personal and professional experiences to the Board, however should always be clear their role on the Board is as a patient, carer or member of the public
- HDR UK will not permit membership to people who are employed by profit-making companies that benefit from access to patient data or where HDR UK otherwise reasonably considers that there may be a conflict of interest. HDR UK will organise further discussions with public contributors with potential conflicts of interest prior to offering of a position with HDR UK.

- Members should, where possible, take an **active role** in Public Advisory Board activities. Should members become disengaged within and between meetings we will discuss how to improve the working relationship and may review the individual's continued membership of the board. This will be discussed and agreed with HDR UK.
- Members are expected to **actively participate** in a minimum of eight of twelve meetings each year. We understand there will be exceptional circumstances in which this is not possible, and this should be discussed with the Chair/Deputy Chair and the HDR UK team so that we can determine the best way to support the individual.

- Honorariums are offered to members for their time at a rate of £75 per meeting. Additional involvement from PAB members will be reimbursed in line with HDR UK policy. This is currently being reviewed and will be shared once approved.
- Members are expected to sign a Non-Disclosure Agreement (NDA) on joining the Board.

HDR UK will cover reasonable travel, and (where appropriate) accommodation, expenses, when agreed in advance. Reimbursement for other expenses, including care responsibilities, may be agreed at the discretion of HDR UK.

MEETINGS AND DECISION-MAKING
- Meetings will take place monthly for 1 hour and 30 minutes.
- The Chair and Deputy Chair of the Public Advisory Board will be appointed by HDR UK in collaboration with the HDR UK Board and members of the Public Advisory Board.
- Meetings will be hybrid or fully virtual. This will be agreed with Public Advisory Board members in line with COVID-19 guidelines. Travel to Health Data Research UK Sites, Hubs or partner organisation may be requested on occasion.

- Meetings will be held under the Chatham House Rule. This is where members are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed.
- Any confidential or sensitive information presented at the Public Advisory Board meetings or shared with Advisory Board members will be clearly indicated.

- Advice provided by the Public Advisory Board is based on consensus, or a majority where a consensus is not reached.

ACCOUNTABILITY
- The Public Advisory Board is accountable to the HDR UK Executive Committee.
- The Communications, Engagement and Insights team oversee the development and delivery of patient, public and practitioner involvement and engagement objectives and support the development and running of the Public Advisory Board.