

Pan-UK Data Governance Steering Group meeting notes: Value Sharing Framework for NHS Data Partnerships

Date:	06 September 2023 1pm-2pm
Venue:	Zoom
Chair:	Cassie Smith
Speakers:	Ralph Evans, Senior Commercial Delivery Manager, Centre for Improving Data Collaboration NHS England Munisa Hashimi, member of HDR UK's Public Advisory Board (PAB).

Introduction

The Chair welcomed members of the Steering Group to the meeting and introduced the speakers and the Value Sharing Framework, noting the parallels with the work of the Steering Group which has delivering patient/public benefit through data at the core of its mission.

Presentations

- **Ralph Evans presented on the [Value Sharing Framework](#)**, a set of guiding principles to help NHS organisations negotiate fair terms for NHS data partnerships, allowing collaboration with academic and commercial partners while ensuring fair return for utilising public data resources.
- This work started in 2020 with collaboration with a wide range of stakeholders on models for data access. The principles presented were built on patient and public feedback, including research conducted by the National Data Guardian.
- External engagement activities were undertaken by BritainThinks, including an online survey of 2000 participants and workshops, including one on how to better articulate the principles. The outputs are available via the Future Platforms on request.
- There are four principles in the framework:
 1. **The cost of access should not prevent good use of data.** Protracted negotiations do not benefit anyone, and a consistent optimised process works better in terms of time and effective use of data.
 2. **The NHS will always charge a fee for accessing health data** to ensure fair terms are agreed for the value of the data.

3. **The cost of access should depend on how data is being used** as well as the type of data being requested. The cost should not be dependent on the nature of the requesting organisation.
 4. **The NHS should share in the value created by its data** proportionate to the NHS's contribution to that value.
- Slides are attached and further resources here:
 - [Value Sharing Framework for NHS data partnerships](#)
 - Data Partnership Guide: [A guide to effective NHS data partnerships](#)
 - [Blog post about how data partnerships benefit patients at the NHS.](#)
 - **Munisa Hashimi presented feedback on behalf of PAB** who discussed the value sharing framework during their August meeting.
 - Munisa noted the variety of differing opinions and thoughts on this topic and detailed three key points:
 1. **Complexity and Clarity.** PAB would welcome clear communications with an emphasis on plain language and more detailed and accessible information.
 2. **Value and Purpose.** There were several differing views on this including the suggestion of a stepwise costing approach to accommodate different stages of research and innovation, and that the NHS should seek a share of commercial value noting that revenue generation should not be the primary objective.
 3. **Accessibility and Inclusivity.** Concerns were raised around the potential exclusion of researchers with limited financial resources due to high access costs. Some PAB members emphasised the need for a public-facing page and downloadable PDFs to make information more accessible to a wider audience. Suggestion of a tier system to ensure fair access, especially for researchers working on areas where funding can be challenging like rare diseases. It was also advised to consider partnerships with commercial entities carefully and the reputational risks involved.

Questions and Discussion

- Q: **Did the concept of public benefit feed in strongly to the development of the principles?**
 - A: Any use of NHS data must have an explicit aim to improve health care in the NHS, including public benefit and service improvements. (See guidance [here](#)).
 - There are nuances around public benefit and the trade off between clinical and economic benefit. The framework has been drafted at a high level to help guide organisations but to allow flexibility in how organisations weigh the principles against each other.
- Q: **Has any work been done to engage the youth demographic?**
 - A: There was no direct engagement with under 18s on this work due to a legal requirement for all public participants in our workshops needing to be over 18.

- **Q: Within the guidance it talks about data access arrangements and anonymised data and pseudonymised data are categorised in the same way -could this cause issues with safe data outputs leaving the SDE? This may cause issues down the line when, for example, commercial parties wish to take data out of the SDE, and this appears to be a deviation from the data access policy for SDEs as it stands.**
 - A: The NHS is looking to the future of national and sub-national SDEs and the current practices with a shift towards the end of dissemination. Claire Bloomfield outlined in a [recent blog](#) how the data landscape is changing in England.
 - In terms of safe outputs from a SDE, the Secure data environment for NHS health and social care data policy [here](#) outlines the approach to safe outputs. Guideline 12 states
 - ‘Outputs from a secure data environment must be assessed and approved and must not identify individuals. All information must be checked before it leaves a secure data environment, including data, code, tools, and any other outputs. There must be robust processes in place to maintain patient confidentiality and to make sure that outputs align with the intentions of individual projects.’
- **Q: Scoping is key to this exercise as there are varying uses for NHS data, including a data-enabled product such as an AI tool, or development of a medicine. There are a significant number of other value costs for the NHS that are considered when these medicines come onto the market. It would be helpful if these distinctions were made to improve clarity.**
 - A: NHSE is keen to engage with case studies to ‘stress test’ against the commercial principles. The framework needs to consider the different purposes and the scope of data use, with consideration to both the financial value and other value of the output. Care also needs to be taken to not inadvertently shut off specific areas of research such as rare diseases ([See guidance here](#))
- **Q: Will there be more guidance on how to apply value outside of financial gain? Also, how do NHSE ensure this framework does not increase the cost of existing research mechanisms?**
 - A: Cost recovery may not apply if there are good reasons for a different approach. Some flexibility and nuanced approaches will be needed. NHSE welcomed case studies from the Steering Group. Please send these to england.improvingdatacollaboration@nhs.net for further discussion.
- **Q: Trade associations have expressed concern over the wording, not in relation to fair value for NHS but consultation with different industry sectors. Clarity is required for all commercial organisations on what is in scope, the transactional cost, royalty sharing etc and the circumstances when each apply. These need to be fair for all that apply for access data.**
 - A: One method for valuing data is to look at its contribution to the ‘foreground IP’ being generated. This can be done by reviewing the characteristics of the data being provided and the intended use.. Further guidance on the value of data would be helpful.
 - The data partnerships guide is a starting point to take a more formal and consistent approach to valuing data. A template is available for data asset management to help organisations think through the resources to value data. Agree that a level of price consistency is needed but might not reach that point for a while.

- **Q: There may be issues around the interpretation of public benefit which can be narrow. Users may need to clarify if the value is not obvious. It is difficult to assign value, there is a huge industry of people working on the circulation of public funds and this could add expense and complexity to the system. Funding comes from a mix of bodies. How to ensure this framework remains on point and doesn't create more costs for the system?**
 - A: The NHS should avoid taking resources away from frontline care to subsidise research. Licenses should not be freely available without recouping marginal costs of accessing that data. Rare diseases research needs to be closely examined to ensure work that is benefitting patients is not stifled. The focus here is on transactability rather than over-engineering partnerships to extract maximum benefit and this will be monitored closely to evaluate greater consistency and clarity over time rather than requiring additional management.
- **Q: The principles are interesting however further detail on the structure and content of the framework is required. Value is dependent on what data will be used for and there is no clear principle of value e.g. cost recovery, commercial value. It is difficult to see how these will work in practice.**
 - A: The framework is high level and simple and the data sharing guide provides more detail. Data access standard values will continue, and they will absorb commercial principles into the approaches including pricing models to get this in place for future offerings. Would be interested to hearing more feedback on models, particularly with industry involvement.

Attending Organisations

1. Administrative Data Research UK
2. Alleviate Data
3. Association of Medical Research Charities
4. Burness Paull
5. Cancer Research UK
6. Clinical Practice Research Datalink (CPRD)
7. Guy's and St Thomas' NHS Foundation Trust
8. HDR UK
9. HDR UK Public Advisory Board
10. Health Care Research Wales
11. Health Research Authority
12. Health and Social Care Northern Ireland
13. Imperial College London
14. Kings College London
15. Leeds Teaching Hospitals NHS Trust
16. Medical Research Council
17. National Pathology Imaging Co-operative (NPIC)



18. NHS England
19. NIHR BioResource
20. Royal College of General Practitioners
21. SAIL Databank
22. Swansea University
23. The Association of the British Pharmaceutical Industry (ABPI)
24. The British Medical Association
25. The University of Edinburgh
26. UK Bioindustry Association
27. UK Longitudinal Linkage Collaboration
28. UK Statistics Authority
29. Understanding Patient Data
30. UWE Bristol