Short update paper for use MY data Executive

Health Data Research Service (HDRS) announcement

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Key points:

- The Health Data Research Service (HDRS) was announced in April by the Prime Minister “to turbocharge medical research”
- It is a partnership between Wellcome and the UK Government
- This is a significant financial investment; £100 million from Wellcome and up to £500 million from the UK Government
- Note that this is UK, not just England
- It aims to:
    - Give approved researchers a single secure route to health data where personally identifiable information has been removed
    - Reduce barriers that researchers face by simplifying access to datasets such as primary care, hospital and mortality data.
- The new service will be housed at the Wellcome Genome Campus in Cambridgeshire
- In their press release, Wellcome made a specific point that that they had also renewed funding for Understanding Patient Data
- There is a commitment that “consultation with patient groups and academic, clinical and commercial researchers will ensure a world-class Health Data Research Service is developed quickly while putting patients’ needs and treating diseases first”

Where to find more information

More details are available in the following links:

- Announcement from Wellcome
- HDR UK response
- HRA response
- Understanding Patient Data Response

I couldn’t see a response from OpenSAFELY who already say that they “deliver research across over 58 million people's health records, always respecting patient confidentiality”.

What might the Executive Group want to consider?

This is a lot of money being invested, and a lot of data involved.

Details are still quite sketchy, but the commitment to consultation with patient groups is something we should see as a way in – we are the only independent patient organisation in this space.

We need to formulate our thoughts about what we can bring to this. Some things that the Executive might want to consider are:

- What role do we need to play, and how do we describe our “offer” to the HDRS development?
- Should we be Helping them to develop/test clearer, coherent messaging about the wider national data strands; FDP, SDEs and now HDRS?
- Can we provide an independent critical-friend role, using voices of informed patients?
- Can we make use of our UK-0wide patient stance?
- How do we describe our “offer” to the HDRS development, and who do we make this offer to?
- Are there funding opportunities available, and what would “conditions” would we need to ask for?
- Are there areas that we don’t want to get involved with?

There will obviously be other points to be considered, so please take this short paper as a starting point for those discussions.