

Amanda Pritchard
CEO, NHS England

10 January 2024

Dear Amanda,

Federated Data Platform contract

We are pleased to see the good progress on the Federated Data Platform (FDP), to make health data more accessible and useful within hospital Trusts. We are also pleased to see the publication of the contract with Palantir. However, we are disappointed to see that a lot of information that is important to patients and the public is missing and we are concerned about the impact this will have on public confidence and trust in the use of patient data.

We understand the need for redaction of some details within commercial contracts. However, the volume of redaction in this contract, combined with the importance to the public of the redacted sections, has the potential to lead to negative consequences for the use of patient data more widely within the NHS and in particular for research.

We are concerned that without more information being available, particularly about the protection of personal data, more patients will exercise opt-outs. While these opt-outs will not affect the FDP, they will certainly affect essential healthcare research and service planning for the future. As a movement with the vision 'Every patient in the UK willingly giving their data to support medical research and their own care', this is of the utmost concern to use MY data and to our Members.

From our values of transparency and trust about the use of patient data, the redacted sections of the greatest concern are:

- **Section 23 - Protection of personal data**

At the very least, is it possible to provide some information about what has been redacted - e.g. operational details or penalties for misuse/mistake? The complete redaction of this section is both puzzling and alarming.

- **Section 05 - The services**

As the NHS is funded by the public, it is desirable to know in full, what is being paid for and what role the public will have in the arrangements for monitoring delivery and value. The data being collected and used is the public's data and the FDP is a service to benefit the public's health.

We understand that, in addition to Palantir, both Accenture and IQVIA and potentially other companies are also providing implementation services related to the FDP. We have not been able to locate the Accenture contract on the 'Contracts Finder' website. The IQVIA contract is on the website but the description of the services is redacted, which we accept given that we understand their role is focussed on managing confidentiality of the information and a detailed description of the service might compromise the technical solution delivering that confidentiality. However, in the interest of transparency, we do think that NHS England should separately provide a full description of the overall service to be delivered by FDP, how the service will work and the roles of the individual suppliers in providing that service.

In addition to the redacted information, we feel that some additional information would improve clarity and thence transparency and trust:

- **Public role in governance**

As suggested above, please provide information about the roles that the public and patients will have in governance arrangements, and at what levels.

We also note that the project plan section is an agreement to produce a project plan. At the very least we would hope to see a deadline or a timescale with milestones for the work and (as noted above) some form of public involvement included.

It is good to know that “NHS England is continuing work on the final redactions, and it is anticipated that additional parts of the contract will be provided in due course...”. Please can you give details of the timescale for the publication? Can you confirm that the sections ‘Protection of personal data’ and ‘The services’ will be released in totality (with the possible exception of the data security elements)?

We believe that this would do much to reassure patients and the public and we would hope this will limit opt-outs for sharing other data, that may be made as a reaction to the detail of the FDP contract information not being available. It would also allow us to strengthen our campaigns and our work in this respect, and to continue to support NHS England in using our health data for patient and public benefit.

Thank you for your attention and we look forward to hearing from you.

Yours sincerely,

Richard Stephens

Richard Stephens
Chair, Executive Group

Dave Chuter

Dave Chuter
Vice Chair, Executive Group

cc Dr Nicola Byrne, National Data Guardian for Health and Social Care
Lucinda Jackson, Collaboration and Innovation Manager, Data and Analytics, NHS England

**The only independent UK movement of patients, relatives and carers
focused on the use of patient data to save lives and improve outcomes**

Our Vision

Every patient in the UK willingly giving their data to support medical research and their own care.

Our Mission

To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data for research and improving healthcare.

Our Aims

- To promote the responsible and accountable use of our data to improve health and health research, and to help to remove barriers to preventing this.
- To highlight the benefits of using patient data for our individual health and for our communities.
- To help ensure patient data is used to create and support an NHS that is better for all.
- To advocate robust and transparent safeguarding of data, which is clearly communicated to patients and the public.
- To provide balance as a trusted voice in patient data, highlighting aspirations and concerns about the use of patient data.
- To act as a critical friend and sounding board to organisations who want to collect, store and use patient data to benefit society.
- To build knowledge and expertise for patients, family and carers to help them play a more active and informed role in discussions and decisions about patient data.

"use MY data to help others and help me"

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