

Amanda Pritchard CEO, NHS England

18 April 2024

Dear Amanda,

### Federated Data Platform contract - follow-up about our previous letter

We are writing in follow-up to our previous letter to you, sent on 10 January 2024. We received an acknowledgement from NHS England's Customer Contact Centre on 15 January, confirming that our letter had been forwarded to your office. To date, we do not seem to have received a reply to our letter.

As detailed in our original letter, we were pleased to see the good progress on the Federated Data Platform (FDP), to make health data more accessible and useful within hospital Trusts, and to see the publication of the contract with Palantir.

However, we were disappointed to see that much information, important to patients and the public, was missing from the contract. We were concerned about the impact on public confidence and trust in the use of patient data, as seen with other patient data initiatives.

We have been waiting for your response, so that we can update our Members - patient advocates who want their patient data to be used for societal benefit. We have delayed publishing our 10 January letter, in order to give time for your response to be received. Three months have now passed and we had expected a response within this period.

However, we were pleased to see the publication of a less redacted version of the contract on 21 March. The remaining redactions, based on protecting the identity of individuals and protecting commercial interest, seem reasonable to us.

Positively, this new version addresses our concerns over transparency and trust relating to details of the protection of personal data and the services which the FDP will provide.

Nevertheless, one important element which still needs to be made clear is 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. Providing information about the roles that the public and patients will have in governance arrangements, and at what levels, would be a positive step.

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 so 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.



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 effective public involvement included.

We believe that the newly published, largely unredacted contract, will 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 will 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 and we look forward to hearing from you by the end of this month if at all possible.

Yours sincerely,

Ríchard Stephens

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Richard Stephens Chair, Executive Group

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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