* use MY data

Draft guidance on NHS England’s protection of patient data

28 February 2023

Introduction

On 23 January the “Draft guidance on NHS England’s protection of patient data” was published on the website of the Dept of Health & Social Care. It describes how the functions of NHS Digital are moving into NHS England.

It is marked as “Statutory guidance” and is a significant document of interest to Members of use MY data.

Noting the word “draft”, the Secretariat contacted NHS England about the status of the document, asking whether this was a formal consultation or indeed whether there was an opportunity to feed back on the draft.

We were told that “we’re not running a public consultation, but we are still working on the draft. If you have any feedback that you or your members would like to share, you are welcome to send it through”.

After discussions, the Executive Group of use MY data recommended that the Secretariat put together a response to reflect the thoughts of the Executive Group. This letter, together with an annotated Word-version of the guidance, is that response.

Additionally, the Secretariat have written to all our Members asking for their thoughts on the contents of the document. We will send through any other points to NHS England as they are flagged by the Members.

Feedback from the use MY data Executive Group

The publication of the draft guidance on NHS England’s protection of patient data was welcomed as helpful. The bulk of the guidance is about moving the work of NHS Digital into NHS England, so is very much about describing how “business as usual” will continue. However, the governance and transparency sections raised some areas which are worthy of further consideration.

Internal governance within a single organisation: As a single merged organisation, NHS England could be in the position of instructing itself on areas of data, so robust oversight will be essential. We feel this needs to be better described.

The new data advisory group: We note that the previous independent oversight group for data access (IGARD) is being replaced with a new “data advisory group”, which drops the word “independent”, as it now includes NHS England officials. We are concerned that this could be seen as an NHS England group which is marking its own homework. The role, remit and authority of the group should be made clear, as should all decisions and minutes. The transparency around IGARD processes and recommendations was developed over many years and should be seen as a starting point.

Transparency: We would like to highlight the different emphasis on publication of the work of the new data advisory group, in particular the uses of the words “should” and “must” in relation to the aspects of their work.

The guidance states (underlined for emphasis) “Minutes of the data advisory group meetings should be published, subject to exemptions under the Freedom of Information Act 2000. Advice and recommendations of the group on any specific third-party dissemination requests must always be published. The minutes should also record where individual advisers are asked to provide advice on dissemination.”

For full transparency, we would like to see these as “must”, not “should”.

We flag this because NHS England have recently replied to a (different, unrelated) freedom of information request saying, “because this is an advisory group, the minutes are not published as standard and [is] not part of the formal governance structure of NHS England”. We think this needs to be addressed. We would like to highlight the benefits of publishing notes from any advisory group, and it is essential for transparency that the new data advisory group minutes are published.

Internal access to data: This also relies on the new data advisory group, so there is a clear risk that NHS England could approve itself for quite wide access to data without scrutiny. On the other hand, there is also a potential benefit that access could be more straightforward. This area of internal data access/approval requires a real commitment to full transparency and involvement of the patient voice. Including details of data flows into “new data environments” is essential.

Data access register: Whilst the need for a data access register is mentioned elsewhere, and that NHS England will take steps to continuously evolve and improve this, we would like to see the importance and significance of this elevated.

Publication of assessment of how effectively NHS England has protected data: This is mentioned in the guidance, but we would also like to see a similar commitment on NHS England publishing information on benefits realised as a result of their collecting and using and promoting third party usage of data.

Technical measures and controls: We thought that this should include an external audit.

Secure data environments: We note and support the commitment that “NHS England should progress towards third-party access to data held by NHS England being through approved secure data environments or trusted research environments that meet the national guidelines”.

Rebalancing the emphasis of data controls with data usage: Whilst the guidance focuses on the duties on controls around actions and usage, we think it should also include a similar duty imposed to use and promote the responsible, legal use of data to improve health and the effectiveness and efficiency of the NHS and to aid the success of UK plc.

Other Government Departments: The guidance does not talk about sharing with other Government Departments directly. Is that covered by the statutory instruments that are mentioned?

Non-Executive Director for Patient Data: use MY data’s Executive Group has proposed that the Board could have a Non-Executive Director for Patient Data. This would aid transparency, patient representation, governance and show that NHS England is working in the best, most appropriate way for patients. We frequently see Boards which have an HR and a marketing expert or other skillset relevant to the business. We think it would be appropriate for NHS England to do something similar in terms of data. Quite a few of the current NEDs have the right background.

* use MY data

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

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Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

Our mission statement

- **use MY data** is a movement of patients, carers and relatives.

- **use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

- **use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

- **use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.

- We work to bring a patient voice to all conversations about patient data.

- We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available here.

- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.

- We provide learning resources for patient advocates on patient data issues, including:
  - Hosting events for patients and the public, focussing on patient data topics
  - a library of resources of data security, consent
  - narratives from individuals about the value of collecting and using patient data.

- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

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