

Draft documents from NHSX

“IG Guidance for Review”

Response from [use MY data](#)

15 July 2020

Introductory Note

This response has been coordinated by the Secretariat of [use MY data](#), on behalf of members.

As with all the responses we collate on behalf of [use MY data](#), these may contain contrasting views from members. It is inevitable that we receive a range of views from members, and all these views are included in our response. We believe that there is strength in presenting a complete range of views.

Contact details and follow-up

Our members are happy for use MY data’s response to be used or shared without restriction.

If you would like to follow-up with [use MY data](#), or ask any questions about our response, please contact the Coordinator, Alison Stone - alison@useMYdata.org.uk

Our comments are provided below and relate to each of the five documents we were asked to review, preceded by some general points of feedback.

Background

Given the short timescales, we sent the documents to the [use MY data](#) Advisory Group members asking for comments on the guidance documents which were supplied by the NHSX Information Governance Policy Team by email on Friday 3rd July. The documents were:

- The duty of care
- Sharing information with the police
- Sharing information with the voluntary sector
- IG guidance to support multidisciplinary teams
- Honorary contracts

We clarified that you were only wanting a patient-voice response to the sections which are marked as “I am a patient/service user”, so our response is largely limited to that area, though there are some wider points which we have made in our submission. We also note that you asked for comments by Friday 17th July.

General Feedback

Some general comments received are noted below:

“I feel that the objectives of these documents is not clear in the mind of the writer(s). Titles are not always consistent when there is no reason for them not to be, some sentences convey absolutely no information and the level of detail provided is not consistent across the documents. Information is not layered, nor links provided (which would be helpful to those seeking additional information). I am struggling to understand what purpose these documents will actually serve.”

“We note that none of the documents make any reference to the National Data Opt-out, which is a flagship policy, currently due for implementation by the end of September 2020.”

And finally, a comment from one member, which is worthy of wider consideration:

“My views remain as they always have been; we need a culture change in governance, replacing Guardians with Sharers, Confidentiality with Access, and recognising that the needs of the many outweigh the needs of the one. We do tend to regard the duty of care as being to the individual but there comes a point when public (or even private) bodies have a duty of care to the public and to society, and I wish the guidance given to these bodies would reflect on that.”

The Duty of Care

The phrase “long term” should probably be written hyphenated as “long-term”.

The phrase “patient/service users confidentiality” should have an apostrophe.

A member noted “I think the public section should tell you what to do if you have a complaint.”

In the professionals sections the document describes the duty to share information but only in respect of providing direct care. Should it not also cover sharing information for research or at least reference one of the other docs where it is covered? At the moment, by omission, it implies the only sharing should be for direct care.

The document states that “The duty of care begins from the moment you start receiving health or care services”. Should the duty not apply effectively from birth, which is when the NHS holds information about you? Similarly, if you are registered with a GP, doesn’t a duty of care still apply even though you are not undergoing treatment? Screening could also fall within this area, as it is not talked about as being “treatment”.

Sharing information with the police

The paper says that “You will be asked before your data is shared with the police”, which implies you have a choice. If this is the case, it would be better to be more explicit.

A specific comment was “Since the NHS and the police are both funded by taxpayers and are there to serve the interests of the public I would have expected this to be written somewhat more positively in terms of dealing cooperatively and effectively and efficiently with requests from the police and, for the most serious cases (e.g. terrorism, serious crime), a statement of the maximum acceptable time for fulfilling requests with a duty to investigate where the time is exceeded.”

The Health Professional section about considering “where you have a choice to provide information to the police”, says that “This includes seeking explicit consent”. From a patient perspective, it would be helpful to be clear about whether consent is always required, or whether it is optional.

Sharing information with the voluntary sector

In the Background section, you might want to say “make” rather than “can make”.

In the professional’s section (the final paragraph) should it say you should ensure that no more than the minimum info needed is provided to organisations providing non-clinical services?

IG guidance to support multidisciplinary teams

One comment was “In the patient section it refers to the team members maybe coming from different organisations. I trust there is a single organisation that is accountable for the care and it is always made clear to the patient which organisation it is. I think the leaflet, in the patient section, should make it clear that that organisation should always be defined to the patient. If there isn’t a single accountable organisation in these circumstances I have a real problem!”

Honorary contracts

The wording might be improved simply to point out that an honorary contract ensures that any volunteers working within an organisation are contractually bound by the same information governance rules as an employee.

Two members noted the same point, “I don’t think it is relevant to patients and so perhaps doesn’t need a patient section. This is based on my assumption that, from a patient’s perspective, all such people can be treated just like everyone else they encounter in the care provider and can, again from the patient’s perspective, be considered an employee or agent of the care provider and so if something is perceived to have gone wrong the care provider is

accountable and, at the limit, the patient can sue the care provider (and not the individual) and the care provider would not have a defence that the person is not under their legal umbrella but is merely on a honorary contract.”

We hope these comments are useful. If any points need clarifying, please do get in touch.

About use MY data

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

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 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 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.

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.

What we do

- ❖ We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.
- ❖ 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 workshops for patients and the public, focussing on topics related to patient data
 - a library of resources of data security, consent
 - narratives from individuals about how collecting, storing and using data can help patients.
- ❖ 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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