

Draft document from NHSX

“IG guidance on using video-conferencing/consultation tools”

Draft undated, received 12 August 2020, response due by 28 August 2020

Response from [use MY data](#)

28 August 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 of 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 shown below and include general points of feedback.

We note that we have been asked only for comments on the patient section, although we have included some comments outside this section, as we thought they related directly to a patient perspective.

General Feedback

As with previous documents that we have been asked to comment on, it contains a mix of the legal and legalistic, some dictionary paraphrases, some bits of plain English and an over-reliance on acronyms.

An immediate example is acronym usage which is not helpful for a patient reader, with one reviewer noting “the very first word [IG] is an acronym that patients will not understand”.

A significant point was highlighted by several patients about “the lack of any practical help contained in the patient section”. The use of video conferencing requires a degree of understanding, and not all patients will have this, or may not have experienced video conferencing before. It was unclear what practical help would be in place to address this.

Whilst trying to restrict our comments to the section for patients, one patient noted that “some of the content for HCPs is equally [unclear] and will be of concern for those who feel they might benefit from reading this document.”

There was a comment about the use of the phrase “service user”. Whilst this may be meaningful to a professional reader, it is meaningless to patients and the public. A similar comment was made about the term “information governance”, which is unlikely to be helpful or understood by the public.

In terms of the recording of sessions, it was clear that the health professional should ask permission of the session was to be recorded, but it was unclear whether a health professional could refuse to agree to the patient making their own recording.

A summary comment from one patient raised significant concern that “there is no depth of understanding of the needs of the type of patient who might read this, or they been completely forgotten during the drafting.”

A linked comment from another patient noted a “plea that they should talk to some patient organisations.”

In terms of the document being more accessible to a patient reader, “in the Further Information section, there should be a couple of links to blogs or guidance from patient representatives or organisations, e.g. the Patients Association, or at least to health charities. At the moment all the links are to NHS or NHS-linked providers not to those of us on the other side of the consultation. This may then be a stimulus for some of our organisations to create some guidance for patients where it often doesn't - yet - exist.”

There is a clear appreciation and recognition from our members that we are being copied into documents at the review stage, but we think that you would benefit significantly from having much earlier input of a patient perspective. This is something we would very much like to explore with you.

As ever, we hope this feedback is useful.

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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