

Consultation by NICE

“The use of broader data and applied analytics in NICE’s work”

Published August 2019

Response from [use MY data](#)

12 September 2019

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 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

Once submitted, this document, will be published on our website - www.useMYdata.org.uk

Is the overall approach set out in the statement of intent clear and understandable?

- 1 - strongly disagree: the statement of intent is not clear and/or understandable
 - 2 - disagree
 - 3 - neither agree nor disagree
 - 4 - agree ✓
 - 5 - strongly agree: the statement of intent is clear and understandable
- don't know / not applicable

Please explain your response

The concept described in the document is clear; that additional uses of existing and new types of data can generate insight into diagnosis, treatment, care and outcomes. This concept is something that has been repeatedly described elsewhere, by NHS England, NHSX, NHS Digital, Public Health England and (more recently) Health Data Research UK.

What is unclear from the document is how the intention (to utilise additional datasets) would be delivered, and how existing and future overlaps in data analytics between NICE and other organisations will be managed.

Of course, the underlying question in the document is that the proposal will fundamentally change the role of NICE, by giving it a new brief in data analytics. This is a substantial change in emphasis for NICE, and it is unclear why they consider themselves best place to undertake this from scratch, what consideration they have made as to how to commission this work from other existing data analytics bodies, or whether they should do this in a formal partnership/networked approach.

Does the statement of intent appropriately take account of current and future trends?

- 1 - strongly disagree: the statement does not take into account current and future trends
 - 2 - disagree
 - 3 - neither agree nor disagree
 - 4 - agree ✓
 - 5 - strongly agree: the statement takes account of current and future trends
- don't know / not applicable

Please explain your response

We would agree that the statement of intent does reflect current and future trends.

However, we reiterate that it is unclear is how the intention would be delivered, and how existing and future overlaps in data analytics between NICE and other organisations will be managed.

Are there any obvious gaps or omissions in the scope of ambition in the statement of intent?

- 1 - strongly disagree: the scope of ambition has no obvious gaps
 - 2 - disagree
 - 3 - neither agree nor disagree ✓**
 - 4 - agree
 - 5 - strongly agree: the scope of ambition has obvious gaps (please outline below)
- don't know / not applicable

Please explain your response

Just to note that the words “scope” and “ambition” are not mentioned anywhere in the document.

Does NICE's ambition appropriately align with relevant external initiatives?

- 1 - strongly disagree: NICE's ambition does not align with relevant external initiatives
 - 2 - disagree ✓
 - 3 - neither agree nor disagree
 - 4 - agree
 - 5 - strongly agree: NICE's ambition aligns with relevant external initiatives
- don't know / not applicable

Please explain your response

The document is about ambition rather than implementation. It is difficult to understand how this relates to the other "external initiatives".

As a rule, we do not think that large national bodies work well together in data analytics areas. If NICE are serious about making improvements, we would suggest their focus is on collaboration rather than repetition.

Does the statement appropriately set out the scope of the data NICE should be considering?

1 - strongly disagree: the statement does not appropriately set out of the scope of the data NICE should be considering

2 - disagree

3 - neither agree nor disagree ✓

4 - agree

5 - strongly agree: the statement appropriately sets out of the scope of the data NICE should be considering

don't know / not applicable

Please explain your response

The scope of the data described in the document is wide. There is a danger that the scope, as written, is simply a collection of “everything possible”, and that the right levels of strategic thought and prioritisation have not yet been applied.

It correctly shows qualitative data alongside quantitative

In terms of the data which NICE already uses, this should be made much clearer on the public website. The mention of HES is contained within a large page on the site which covers many other things. Other datasets which NICE already uses (Primary Care Mortality Database [PCMD], Central Practice Research Datalink [CPRD], the Health Improvement Network [THIN], QResearch) are currently not mentioned in the Privacy Notice.

For transparency, there should already be a section which is written from the perspective of an individual, which should be clear, complete and easy to understand, describing what patient-data is already used. This needs to be done straight away before a new set of additional datasets are considered.

What steps should NICE take to maintain transparency and support validation and reproducibility in the use of applied analytics?

Firstly, be transparent about the data that NICE actually hold. Transparency around the analytics should include the publication of metadata together with results, and the publication of algorithms as they are developed to allow peer review.



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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