

## Consultation by NHS Digital and the Private Healthcare Information Network:

### [Response from use MY data](#)

**Subject:** ADAPt Consultation

**Document:** “Private Healthcare Information Reporting Change Proposal”

**Closure:** May 22, 2020

**Sent to:** enquiries@nhsdigital.nhs.uk

#### **Background to the consultation:**

The Acute Data Alignment Programme (ADAPt) has been initiated between NHS Digital and the Private Healthcare Information Network (PHIN) to explore how data collected by PHIN from UK private healthcare could be aligned to NHS data standards and integrated into relevant NHS quality and safety reporting systems

#### **Introductory Note**

We asked the members of the use MY data for views on the content of the consultation, which we have incorporated into a coordinated use MY data response.

We have also drawn from previous work we have done with our members, within our workshops and other projects which we have undertaken, to bring as wide a response as possible.

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 will receive a range of views from members, and all these will be included in our response. We have always seen our ability to represent contrasting views as a strength.

This is clearly a large consultation document, so members have made some brief comments which we are highlighting to you which you might want to consider.

Our members have been extensively involved in conversations about the uses of wider data, and have previously responded to consultations on Artificial Intelligence, the Centre for Ethics, the National Data Guardian and the National Data Strategy.

We note that you have already engaged with a number of stakeholders on the proposals set out in the consultation, including representatives from independent

and NHS Hospitals, along with professional bodies and associations representing consultants<sup>1</sup>.

We also note that you have set up forums to discuss specific topics including the technical, privacy, information governance and provider organisational implications of the changes. Have you also considered a similar discussion forum which would be aimed at patients and the public? Perhaps this is something which we could discuss with you if this is of interest?

## Summary

We hope that the comments from use MY data are helpful.

We are happy to be contacted by the consultation team, and we are happy for our response to be shared as required by the consultation team. Our response, once submitted, will also be added to the use MY data website ([www.useMYdata.org.uk](http://www.useMYdata.org.uk))

Any contact should be made through Alison Stone, use MY data Coordinator, at [alison@usemydata.org.uk](mailto:alison@usemydata.org.uk)

## On behalf of the use MY data Advisory Group

A handwritten signature in grey ink that reads 'Alison Stone'.

**Alison Stone**

Coordinator

use MY data

[alison@useMYdata.org.uk](mailto:alison@useMYdata.org.uk)

A handwritten signature in grey ink that reads 'Chris Carrigan'.

**Chris Carrigan**

Expert Data Advisor

use MY data

[chris@useMYdata.org.uk](mailto:chris@useMYdata.org.uk)

[www.useMYdata.org.uk](http://www.useMYdata.org.uk)

@useMYdata

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<sup>1</sup> Proposal document, page 4; [https://nhs-digital.citizenspace.com/dis/adapt/user\\_uploads/adaptchangeproposalconsultation\\_v1.9.pdf](https://nhs-digital.citizenspace.com/dis/adapt/user_uploads/adaptchangeproposalconsultation_v1.9.pdf)

## Detailed responses to consultation questions

5. Please provide any comments on the vision, aims and expected outcomes of the ADAPt Programme (Section 3)

We recognise that private healthcare provider data have not to date been included in many of the national quality and safety reporting systems.

We also note your statement that “Systematic failures of patient safety in the NHS and private sector have recently been reported by the Independent Inquiry into the Issues raised by Paterson and are also currently being investigated by the Independent Medicines and Medical Devices Safety Review”.

We would agree that unless comparative data are collected, collated, reported and published, it will not be possible to assess the quality of care delivered in the private healthcare sector. To this end we would encourage the adoption of standard measures across the NHS and private providers.

We recognise and support the fundamental principle of transparency as described in the proposal.

Your collective vision states:

“To bring about an alignment in data standards, measurement and reporting systems across NHS and private healthcare in order to enable greater transparency in quality and safety and to support patient choice and opportunities for improving patient care.”

Some thoughts we received back include comments about the scope and ambition of the current proposal, specifically:

*“I’m not excited about the information that will be collected but I think it is a necessary step.”*

There may be a challenge in explaining the details of the proposal to patients who are not embedded in the existing data flows of the NHS, as evidenced a member who commented:

*“I imagine the data collected is very similar to HES Data (not that I have seen the HES Data Dictionary).”*

If you are scoping any wider communications about this to a patient community, this is something that should be considered carefully. We would be happy to talk to you about

ways that use MY data has done this type of communication and co-design activity with patients, relatives and carers on may complex topics around the use of patient data.

Some other points which we would emphasise about your stated aims, and which underpin the philosophy of use MY data are shown below.

#### Making data visible

Our stance is that where data has been provided by patients, then this data should be used for the benefit of patients.

#### Reducing the burden of data collection

We would rather emphasise that data collection should be seen as routine practice, which is designed to allow comparative outcomes to be understood. If data collection is seen as a burden it will always be an uphill struggle, playing a minor role to the “more important” priorities. Data is fundamental. Data saves lives.

Some specific comments following member responses, relevant to this question, are:

“It will allow some basic safety monitoring of in-patients (what % of the consultant’s patients die within three months etc) and could spot patient exploitation (why does that consultant always do this additional procedure when, in the NHS, it’s rarely done) but I’m not certain of further benefits but, as above, it’s a necessary first step.”

“It doesn’t address the standards of clinical records in private care and, since it presumably goes into the HES repository, it won’t be immediately available when the same patient turns up at another hospital (private or public). In that context, I met a surgeon from [named hospital] yesterday and she said she regularly gets fully compos mentis patients turning up with three big scars who can only remember what two of them are for and the referral has no info. I’d like to propose we should have a National Health Service.”

“Not very helpful but, to me, it’s a very innocuous consultation. Whether the private providers agree may be another matter.”

“One of the problems I have as a patient is that when anything happens to me - I don't think of it as data. Most of us don't. But when things do happen to us, we have some pretty common questions. What's going to happen to me? If I take this medication what will happen to me? We know about drug symptoms, for instance, because of data from patients.”

use MY data member

6. Please provide any comments on the guiding principles of the ADAPt Programme (Section 3)

We had no substantive comment on your “Guiding principles”, but these appear coherent, with the caveat about the term “burden” when talking about data collection. We have made this point earlier in this response.

High-level outcomes

Our members have previously recognised the benefit of their complete medical record being available to their treating teams, so would be supportive of this point. However, does this also mean that the combined medical record will also be available to private providers?

The proposal highlights the benefits of analysing complete data across complex pathways which involve private and NHS-funded care), but it is not clear where this analysis would take place, nor what access-controls would be in place to ensure the data would be used effectively. We have made this point in our response to your Question 8.

7. Please provide any comments on implications or concerns relating to the organisational aspects of this change proposal, such as policy or business processes (Section 5)

Have PHIN or NHS Digital considered any patient-oversight of the process and the results?

8. Please provide any comments on implications or concerns relating to the technical aspects of this change proposal, such as changes to systems, data flows or standards (Section 5)

Would this project include the cancer flows which go to PHE?

There was a question as to the legal basis of PHIN to receive data from NHS Digital, which was not clear. This is important for transparency.

Whilst the document says that any data access requests for the submitted data will be managed through the existing Data Access Request Service (DARS) inside NHS Digital, it wasn't clear whether this would have any oversight by your independent Group, IGARD.

Specific points of clarity were requested:

“Will private data also be directed to registries and audits. NHS hospitals can spend multiple weeks processing data for audits such as the SNAPP (stroke) audit, or checking data before submitting to NCRAS. It's in audits such as NABCOP that variation in care and outcomes (such as Paterson visibility will be detected)”.

“Is only acute data being incorporated, and exactly what does 'acute' means (inpatient?) given the Paterson reference and mastectomy's being offered as day case out patients.”

9. Please provide any comments on implications or concerns relating to the financial costs or other burden aspects of this change proposal, such as costs for changes to systems or potential increase or reduction in burden (Section 5)

This question raised several different points across the membership. Overall, the proposal for data sharing from the private providers was well received.

The question of any costs, and how these would be met, did raise some discussions across the membership. In relation to the collection, transfer mechanisms and data quality assurance, several points were highlighted, typified by questions including:

“Will the private sector pay for the transfer infrastructure”

“Will the private sector providers send their data to a safe haven for cleansing - paid for by them - so that the data coming in is already fit for the recipient data base. If not this is then a new burden and cost”.

“...it does not seem unreasonable that any private hospital/group bear their own costs of collecting & extracting data in the agreed format (with agreed data quality validations) & providing it to the NHS/PHE. What seems unreasonable to me is the private sector having to bear costs incurred by the public sector in processing that data as they have no control over those activities or costs”.

“Although the private sector does benefit from the public sector - negotiating national drug prices for example; running clinical trials to validate new medicines and therapies, recruiting and training staff, funding medical schools... Being informed by the findings from the data processed and analysed by public sector analysts cost-free...”

One comment covered the thoughts of several, “Private hospitals should be treated just like NHS hospitals as far as cost recovery goes”.

The debate was nicely summarised in:

“The private sector and the public sector health exchanges just immediately bring into the open the principle of fair reciprocity ...based on the concept of mutual exchange where everyone matters equally

“That doesn’t though happen ..covid 19 making that temporarily transparent...”

“Does the private sector fairly carry the burden of and obtain the benefit of health care with the NHS across the population...”

“I agree with all of [the different] observations...it’s just for me a continuous need to bring ethical scrutiny...fair exchange.. into the private sector public sector health care transactions....

“My expectation is that the private healthcare providers will transfer this information without cost to the NHS/PHE”

10. Please provide any comments on implications or concerns relating to the data protection, privacy and confidentiality aspects of this change proposal, such as concerns over potential for unclear collection, processing or data sharing by NHS Digital (Section 5)

The proposal was not clear what steps the private hospitals are taking to ensure their patients are aware of the new data flows which are being proposed. Is a separate Privacy Notice going to be produced by PHIN or by each private hospital? Our members have previously commented on the different quality of patient communication materials which they have encountered through their care, and this could be an opportunity to move to a standardised approach.

As one member noted:

“I can imagine that there could be some patients who, for whatever reason, might prefer their private health data not to be included in their own NHS record. I wonder if such combining of data on an individual patient record should be subject to patient consent.”

The document states that any patients who have expressed a preference by using the National Data Opt-out (NDOO)<sup>2</sup> will have that preference respected. More widely, there remains confusion over the relationship of the different opt-outs for the NDOO and the Summary Care Record opt-out<sup>3</sup>.

It was unclear from the PHIN website (using the link which was included in the proposal), whether the role of the patient voice played any part in the governance of PHIN.

We would encourage PHIN to adopt the Patient Data Citation, which was developed by the members of use MY data and which has been adopted widely by analytics and research organisations.

“My suggested solutions to some of these problems is actually to get patients involved in data. But just don't tell them it's data. Get them to sit on a committee or a group where they have a specific function.”

use MY data member

<sup>2</sup> NDOO; <https://www.nhs.uk/your-nhs-data-matters/>

<sup>3</sup> SCR Opt-out; <https://digital.nhs.uk/services/summary-care-records-scr/summary-care-records-scr-information-for-patients#opting-out>



11. Please provide any comments on the potential implications or barriers to future closer alignment of private healthcare data with systems and processes for NHS funded care  
(Section 6)

As a movement of patients, relatives and carers we are supportive of the collection and reporting of patient experience data, as a key outcome measure. We would expect that where patients have taken the time to complete surveys and questionnaires, that this would be analysed and reported openly and transparently.

## 12. Do you have any further comments?

A few summary points are worthy of note, encapsulated by:

“For me this proposal is long overdue, so I'm afraid I tend to think "Get on and do it and tweak it afterwards as and when needed".

It was also noted by one member that we do not know how many of our membership have actually been treated privately and therefore would be affected by the proposal directly. In response, one member volunteered:

“As a private cancer patient and an NHS patient I guess I need to comment. I'm reluctant because I was eaten alive at a talk I gave at the [redacted] conference early on in my Patient Advocacy life which advocated for private records to be shared with the cancer registry. At that point I didn't realise how political and ££-centric these data flows were!”

“I want private healthcare included in national data flows because unless private records are shared, the data is not only incomplete, it's dirty. I saw my own record: it shows diagnosis only (sent by NHS) and zero treatment (provided by Private). Using NCRAS data alone it looks like I survived without any treatment. The presence of these partial records compromises the value of observational analysis... and this is now even more important given that real world data is now being used by the FDA for licensing drugs (e.g. recent male breast cancer drug).”

“So, yes, I'm fully backing the ambitions of ADAPT.”

The only additional comment was made by a member from Scotland, who commented:

“This doesn't apply to Scotland - but to me should & may in future.”

## 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.

**[www.useMYdata.org.uk](http://www.useMYdata.org.uk)**  
**[getinvolved@useMYdata.org.uk](mailto:getinvolved@useMYdata.org.uk)**  
 **[@useMYdata](https://twitter.com/useMYdata)**