Consultation by the National Data Guardian:

"National Data Guardian for Health and Social Care: a consultation about priorities"

Response from use MY data

Closure date: Friday 22nd March 2019 to ndgoffice@nhs.net

Introductory Note

The National Data Guardian has requested views on this consultation from those with an interest in the use and safeguarding of health and care data, seeking to hear from a wide range of voices, including patients, the public and those who use health and care data every day in their jobs.

The consultation is seeking advice on the key priorities for the new National Data Guardian role, setting out four proposed priorities and potential areas of interest for the National Data Guardian within each of these.

We note that these are not the only things the National Data Guardian will do.

The consultation asks for feedback on these priorities from stakeholders. As a patient movement with a specific focus on data, we always directly represent the views as expressed by patients and carers when responding to consultations. At times this can illicit contrasting responses to specific questions, and there may not be a clear consensus of opinion.

In producing this response, we asked the members of our Advisory Group (patients and carers) for their thoughts, comments or questions. These have been collated by the use MY data Secretariat into this use MY data response.

Priority 1: "*Encouraging access and control: individuals and their health and care data*"

<u>Consultation questions</u>

1. Should giving people access and control of health and care data be one of the National Data Guardian's top priorities?

There was not wholesale support as to whether giving people access and control of health and care data should be one of the National Data Guardian's top priorities. There was also concern that making it the first priority (number one) may give the impression it is the Guardian's TOP priority.

We agree that patients should be allowed access to their own health data (we would assume this to be digital data and images). We consider this would have several benefits, including highlighting areas of poor data quality, but also in the areas of additional patient-suppled data.

To be clear, in an ideal world we would support this, but we have serious concerns that this could mean bringing the NHS to a grinding halt, in which case this was not seen as a priority.

On the control element, there is a clear need for much more transparency over how our data is used and by who, which we comment on later. We feel that the current situation regarding how patients can opt-out of certain uses is becoming increasingly confused. The simple question which is asked for the National Data Opt-out is increasingly seen as too simplistic, and our members are reporting that different approaches are being examined locally and regionally by the Local Health Care Record Exemplars which may result in increased confusion rather than reassurance.

In particular, concerns were expressed that if dynamic consent is a public priority this would have considerable administrative overheads. We would also question whether the public appetite for this really exists.

2. Are the outlined areas of National Data Guardian interest the right ones for the National Data Guardian? (Please tell us if there are other areas we should be looking at under this theme or if you think others are better placed to do this work)

We think the areas are correct, but would make some additional points:

The National Data Opt-out

The public awareness of the National Data Opt-out needs to remain on the list. This should be a top priority. We have commented further on the National Data Opt-out elsewhere in this response.

Patients and their own data

There are potential benefits in patients having much simpler access to their data. One area which has not received enough focus is in data quality.

If we are to move to a position where we have data that is actually valuable for real world evidence, we need to recognise that currently, routine data is often too poor to analyse.

Rather than simply safe-guarding data, questions should also be centred on how to improve data quality (correctness and completeness). We note the potential for patients to supplement NHS data with their own, either directly or from private institutions.

Seeing where our data gets used

There is a strong feeling that we need an improved understanding and narrative of how and where patient data is used. This would also highlight where data is not used, and where data is available to health professionals but not to patients.

Some examples of this were:

- Lack of (aggregated) data sharing: many Oncologists do simple reporting on their own patients (like how many patients have they seen and how many patients died). Either they don't get access to this information

through the Trust/National reporting (or they don't trust the quality of the data that is nationally reported). So their only way of getting this is by creating their own excel files/access databases which are limited by their own patient volumes and experiences.

- Less common diseases: in cancer services, patient volumes don't exist at a Trust level to provide robust analysis on anything other than the 'Big 4' cancers. The rarer cancers need data sharing beyond the Trust.

Seeing where our data isn't used

Where analyses based on patient data are produced, we would look for assurance that reports, such as those from national audits, are read and translated into clinical practice. Equally, knowing how these are used to take action when they evidence poor care is important to patients. This should be made clear in an accessible manner, to highlight the benefits of sharing and usage for patients and the public.

It has also been noted that several analytical reporting tools (such as the PHE Cancer Stats portal) remain inside the NHS Network and inaccessible to patients, even when these portals do not contain any identifiable data and have (or can be) suppressed for small numbers. Given that these tools are produced using patient data, it is wrong that they are not accessible by patients, third sector organisations and others.

3. What would you like to see the National Data Guardian do in this area?

We would like to see a continued focus on transparency. This should include working with (and through) key groups such as Understanding Patient Data and use MY data, and others.

As reported at a recent event in London, NHS Digital's chief executive Sarah Wilkinson has warned a confused policy on data sharing risks sowing "deep and almost irreparable" public mistrust. The existing mistrust is already "slowing us down" on sharing data to improve care, with clinicians in particular "anxious about sharing it with the health research systems because they don't feel they can be completely confident in its uses". The National Data Opt-out is described as not "sophisticated enough".

We would note the work that use MY data is undertaking, which sits alongside work being undertaken by NHS Digital, is highlighting some serious areas of concern over the lack of transparency, communication and understanding around the transition from Type-2 opt-outs to the National Data Opt-out, in particular relating to historic opt outs.

Priority 2: Using patient data in innovation: a dialogue with the public

<u>Consultation questions</u>

4. Should Use of patient data in innovation be one of the National Data Guardian's top priorities?

We have heard that it is difficult and costly in terms of time and effort for Trusts to deliver commercial real-world evidence studies. Our understanding is that it can take several years to get a Trust to sign a contract to share data with a commercial company. Individual Trusts have the power to decide to do this - but as there is no single NHS role that is responsible; the choice is bounced between oncologists, commercial, IT, R&D, data protection officer (people who often don't really understand the benefits/challenges of real-world evidence and its complexities).

We would agree that innovation can be seen as a key theme, but these problems need to be addressed.

We believe that the National Data Guardian should give particular attention to the commercialisation of the national data asset. Whilst we have some discomfort with the use of the term "commercialisation", we believe that this needs to be undertaken in a way which produces benefit both to patients and financial or other benefits to the NHS, all being tangible and transparent. We should not be blindly driven by dogma (either for or against) on this point but take a sensible, well-considered view. We see the National Data Guardian as having a role in this.

We would also highlight the fundamental issue of data quality.

5. Are the outlined areas of National Data Guardian interest the right ones for the National Data Guardian under this priority?

Our simple response would be that the National Data Guardian has to set about explaining the moral contract and the benefits of sharing data. Data generated by a public healthcare system should be used for public benefit.

We need a much stronger narrative on what it is ok to share for the national good, and how to do it. We would like to see a shift from the starting point of

"Don't, Can't and Mustn't" to what you "CAN" do and indeed what's important that you "DO" do. This includes sharing medical data for the health of the nation.

The National Data Guardian has regularly noted that "data saves lives", so we need to be equally clear that not using data could cost lives.

As a patient movement we firmly believe that, quite simply, difficulties around data access have damaged research and cost lives.

6. What would you like to see the National Data Guardian do in this area?

As a patient movement, use MY data considers itself to have a key role in bringing an informed and engaged patient voice.

We coordinate patient views and questions and run national workshops which bring together patients and carers with health professionals, policy bodies, commercial companies and privacy groups, to look at a common problem and come up with collaborative solutions.

Our experience in working with similar patient groups is that there are difficulties in obtaining funding for such work, despite all members giving their time and input for free. There is a fundamental inequity in the contrasting levels of investment in technical infrastructure and research (which uses patient data) when compared to the minimal investment in an engaged patient voice. We would like to see the National Data Guardian giving her backing to modest investment in such patient/public involvement activities, regardless of the specific organisation, or organisations, that carry it out.

Priority 3: Getting the basics right: information sharing for individual care

Consultation questions

7. Should Getting the basics right: information sharing for individual care be one of the National Data Guardian's top priorities?

Yes. We would highlight that this should include the basics of data quality (accuracy but above all timeliness) and inter-operability – this should be the very top priority.

8. Are the outlined areas of National Data Guardian interest the right ones for the National Data Guardian under this priority? (Please tell us if there are other areas we should be looking at under this theme, or if you think others would be better placed to do the work)

These would seem appropriate, although timescales are unclear and would need to be developed. As a patient movement, we would encourage the inclusion and engagement of patient groups such as ours in being able to enforce this message.

9. What would you like to see the National Data Guardian do in this area?

As this section is talking about getting the basics right, we would like the National Data Guardian to undertake audits of NHS IT to ensure that all organisations are doing what they promised to do on the basics before moving off into other areas.

Priority 4: Safeguarding a confidential health and care system

<u>Consultation questions</u>

10. Should Safeguarding a confidential health and care system be one of the National Data Guardian's top priorities?

We have commented elsewhere about the need to prioritise usage and benefits alongside the area of safeguarding. We would make the point that safeguarding is essential but should not be at the expense of appropriate sharing and usage. We are concerned that the in the past there has been a 'play it safe' culture of obstructing data sharing to the detriment of public benefit.

11. Are the outlined areas of National Data Guardian interest the right ones for the National Data Guardian under this priority?

We would agree that the interplay between common law and data protection law needs to be considered urgently. This should include dialogue and the production of clear guidance from the Information Commissioner's Office.

12. What would you like to see the National Data Guardian do in this area?

We would expect the National Data Guardian to act in a leadership and coordination role.

Additional consultation questions

13. Looking at all the priorities outlined, are there other areas of work that you would suggest for the National Data Guardian?

We have no comments on this point, other than to restate what is included in the rest of the response.

14. Are there any priorities you would remove or change? (Please explain why and what you would like to see the National Data Guardian doing.)

We have no comments on this point, other than to restate what is included in the rest of the response.

15. Please provide any other comments or feedback to the National Data Guardian and her team.

We have highlighted some overall points below which may not have fitted directly into the questions above.

<u>Shifting the focus from just safe-guarding to include usage and benefits</u>

We note and very much appreciate Dame Fiona's comment on her appointment that:

> "I look forward to taking up the role on this new basis and continuing to work alongside others to build public trust that patient data will be used appropriately and effectively" *(emphasis added).*

This theme was also echoed by Nicola Blackwood, who stated that:

> "Placing the National Data Guardian on a statutory footing strengthens the role as an independent and authoritative voice for the patient on how their data is used in the health and care system. It is right that patients are confident they have a strong champion not only to advise them but also to challenge the system and ensure that confidential information is safeguarded and used appropriately."

> "In establishing this role Dame Fiona has firmly rooted the National Data Guardian within the health and care system as an essential building

block for building public trust for the use of patient data." *(emphasis added).*

As highlighted in the red text above, our members would make the point that so far, the National Data Guardian has concentrated on safeguarding data. We would like to recommend that the role should give more emphasis to ensuring data is actually made available for public benefit.

It was noted by several members that by having a National Data GUARDIAN, there is a danger that this sets the scene for people not releasing data and not letting anyone (legitimately) see it. We have heard that a "risk-averse, bunker and barricade-building culture" has then been reinforced by the National Data Guardian's initial focus on keeping things safe and secure. This seems to have been at the expense of data usage.

In essence, we have seen that organisations have found it easier to "keep the door locked and bolted". This needs to change.

Governance

As an active patient movement, many of the use MY data members are similarly active in local and national data, analytical and research groups. They have seen how patient and public members add legitimacy and bring new perspective, and are absolutely aligned to the role of patients and the public playing an equal part on the groups and committees. It has been highlighted that, in contrast, there is no patient representation on the National Data Guardian's group. We see this as something which needs to be addressed.

We would similarly encourage any committee that authorises data sharing to consider the inclusion of independent observers to their meetings.

Summary

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

Our overall message is that, so far, the National Data Guardian has rightly concentrated on ensuring that data is not misused. We think this is appropriate because preventing misuse is the foundation on which a more outward looking focus can then be built.

However, our view is that the National Data Guardian should now have an equal focus on making sure that data is made more accessible to researchers where it is appropriate. The role should be seeking to flush out wilful hoarders of information or organisations that create arcane, overly bureaucratic, inconsistent processes that inhibit legitimate access to data. NHS data (despite well understood shortcomings) is probably as good as it gets around the world and so we must seek to ensure this national asset is used to drive forward the health of the nation, in a fair, open and transparent manner.

As a patient movement we firmly believe that, quite simply, difficulties around data access have damaged research and cost lives.

We thank you for the opportunity to feed into the consultation process and hope that use MY data members will be able to play a part in the work of the National Data Guardian.

As we stated in our response, if we accept that "data saves lives", we need to be equally clear that not using data costs lives.

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
getinvolved@useMYdata.org.uk
@useMYdata