

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

Response from the Faculty of Public Health

Introduction

The **Faculty of Public Health (FPH)** is a registered charity and a joint faculty of the three Royal Colleges of Physicians of the United Kingdom (London, Edinburgh and Glasgow), with more than 4,000 members. Its aims are to promote for the public benefit the advancement of knowledge in the field of public health; to develop public health with a view to maintaining the highest possible standards of professional competence and practice; and to act as an authoritative body for the purpose of consultation and advocacy in matters of educational or public interest concerning public health.

This submission has been prepared in collaboration with the **Health Statistics user group (HSUG)**.

In this submission, we focus mainly on those issues of greatest importance to improving the health of the population as a whole, including points relevant to understanding of the wider determinants of health, and reducing health inequalities. While all the areas mentioned in the consultation document are important, we have left commenting on matters focusing more on clinical uses of data or the rights of the individual patient to others.

The seventh Caldicott Principle, mentioned in relation to Priority 3, is equally relevant to enabling the use of information for research, planning and service delivery as it is to patient care. We encourage the NDG to pay increased attention to the public health perspective and the benefit to society of ensuring efficient and complete flows of data for those purposes. We would like to see the NDG play a leading role in clarifying good practice on data access, sharing and linkage, and achieving consistency of rules and practice across organisations.

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

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

From the perspective of public health, this is not a top priority in itself. There is limited immediate benefit to the health of the nation as a whole, although enabling a more engaged and empowered public and fully-informed patients is clearly a desirable long-term aim. On the other hand, there are risks:

(a) Unless handled with great care, increasing patient access to records as described has the perverse potential to increase health inequalities. This is because the ability to benefit from increased access to records is likely to be concentrated among the more affluent, educated, assertive and digitally connected members of society. There is a clear risk that those unable to benefit – likely to include the socioeconomically deprived, elderly, people lacking higher education and those whose first language is not English – could find their existing disadvantage increased as a

result. For an overview of this subject, see *Digital inclusion guide for health and social care* (NHS Digital, April 2018)¹ and *Exploring the UK's digital divide* (ONS, March 2019)².

(b) More decision-making by patients about use of their data, such as for research, is ethically desirable. However, this aim has to be balanced with the public interest or 'common good', which is also a valid ethical aim. It is well-established that some uses of health data depend on more or less complete population coverage, and/or ensuring that incomplete data is representative of the population. Increasing use of opt-outs potentially presents a risk to health research and the use of data to improve public health, unless carefully constrained in its application.

2. Are the outlined areas of NDG interest the right ones for the NDG?

Under this heading, we consider further work to clarify the nature, role and handling of opt-outs to be a matter of urgency. The issues to be addressed include legal points which have yet to be resolved, such as the rights of children vis-à-vis their parents and carers; clarifying the scenarios to which opt-outs should or should not apply; achieving a shared understanding among government and NHS stakeholders on how opt-outs should operate; designing a practicable and efficient set of inter-operating procedures for the application of opt-outs where necessary when sharing and/or linking data between organisations; and ensuring accurate, clear and consistent communication with the public around this subject.

3. What would you like to see the NDG do in this area?

The NDG is well-placed to:

(a) Facilitate discussion among the public and professionals on the interaction between patient rights and the public interest in the context of opt-outs, and continue previous work on the limitations of opt-outs in a research context.

(b) As part of the above, promote focus on the use of data for the 'common good' in terms of public health practice and research as well as other research purposes. This must be in a manner which is engaged with the public (see below).

(c) More widely, lead a debate on the social and ethical concepts around ownership and use of data in the light of 'big data' innovation and large-scale data-driven research.

(d) Bring together stakeholders to reach agreement on outstanding issues relating to opt-outs (see Question 2 above).

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

4. Should use of patient data in innovation be one of the NDG's top priorities?

From our point of view, the sole focus on 'innovation' is unhelpful. Where there is innovation there must be evaluation. Much worthwhile actual or potential use of health data is about describing population demographic and social factors, linking health outcomes to other data sources, and so on: not only about technological advances. However, taking a wider view on using patient data in

¹ <https://digital.nhs.uk/about-nhs-digital/our-work/digital-inclusion>

²

<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

research and public health improvement, we support this area as a priority as long as appropriate evaluation is included as a requirement.

5. Are the outlined areas of NDG interest the right ones for the NDG under this priority?

Continuous work is required to uphold public trust in the NHS and government over the use and sharing of data. The NDG should play a leading role in exploring key issues such as the balance of patient's rights vis-à-vis the public interest and how this is discussed in the public domain, and the acceptability of access to NHS data by commercial enterprises. As both technology and public perceptions can change, it will be important to engage with the public through surveys, qualitative studies and consultations on an ongoing basis.

In particular, while surveys done in the recent past have shown that the public has a positive view about the use of health data for research and related purposes and more negative views about commercial and other uses, the NHS Digital Opt-out service allows only a single 'blanket opt out' from use of data for 'research and planning'. The possibility of a more nuanced opt-out system therefore needs to be explored.

Scotland and Wales have made considerable advances in the linkage and analysis of administrative health data and considerable progress is now being made in Northern Ireland. The same progress has not been made in England because of barriers to data access. Because this has hampered work on research which has been funded in recent years leading to waste of research funds, funders are reluctant to fund further research in this area and it is difficult to obtain funding for research. We should like to see the National Data Guardian take a positive approach to the use of administrative data and data linkage in public health research and practice, subject of course to the appropriate safeguards to protect confidentiality. It is important to remember the extent to which health research is funded by the public through voluntary donations and fund raising, to a significant extent in conditions such as cancer and heart disease.

The specific mention of a 'reciprocal relationship' seems to raise ethical questions of considerable complexity. Clearly access to healthcare must not be made conditional on consent to certain uses of data beyond immediate care (and is implicit in the CMO's future report in the NESTA scenario). The usefulness of exploring public perceptions on this concept is not clear.

We would emphasise the 'increasing interest in linking health and care information with other sources of data' mentioned in the main text as a key area to be developed, which merits being added to the 'NDG areas of interest'. This is a major current interest for both public health practice and important areas of social and health research. Legislation and data access procedures as developed in practice have created barriers which frustrate analysis for the public good, while different government and NHS bodies have been inconsistent in their rules and processes.

We also emphasise the importance of risk stratification and data linkage as potentially the most significant life-saving intervention using patient data. The development of this area is currently hampered by inappropriate and over-restrictive application of data protection rules by some organisations.

6. What would you like to see the NDG do in this area?

The NDG should play a leading role in:

(a) Ongoing engagement with patients and the public to understand perceptions on the research use of data, data sharing and linkage. The NDG could commission research and consultation on public

understanding and opinions on these subjects, or work with others to promote such activities, disseminate the results and draw out relevant lessons.

(b) The above should include seeking public opinion on key issues such as commercial access to health data. A thorough discussion and clear guidance on this topic would be widely useful.

(c) Achieving a shared understanding between all NHS and government bodies of the needs for different kinds of data use in the public interest, the appropriate legal gateways and ethical issues. There is an urgent need for greater coherence across all organisations handling and releasing health data, and impetus to drive forward initiatives for more joined-up data access processes so that the benefits of research and planning based on health data (and linked health and other data) can be realised.

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

7. Should getting the basics right: information sharing for individual care be one of the NDG's top priorities?

This area is clearly of great importance. In particular, clarifying the situation around sharing information with non-NHS staff is essential for ensuring an integrated health and social care system.

8. Are the outlined areas of NDG interest the right ones for the NDG under this priority?

Some conceptual work is needed to consider the boundaries of data sharing in the context of 'big data', data from mobile healthcare devices or apps, and so on. However, encouraging better sharing across organisational boundaries is the most important issue in this priority area.

9. What would you like to see the NDG do in this area?

The areas of interest and matters identified in the main text seem appropriate.

Priority 4: Safeguarding a confidential health and care system

10. Should safeguarding a confidential health and care system be one of the NDG's top priorities?

This area is clearly of great importance, however the responsibility of safeguarding health data in practical terms sits more with NHS Digital, Public Health England, the Health Research Authority and other organisations.

11. Are the outlined areas of NDG interest the right ones for the NDG under this priority?

The points mentioned are pertinent, and more clarity would be welcome. However, in comparison to the other priority areas mentioned in the consultation, these are very specific legal issues, and the NDG's involvement seems less urgent.

12. What would you like to see the NDG do in this area?

Some engagement with relevant stakeholders, and integration of these issues into wider work around public understanding and opinions, would be welcome.

Additional consultation questions

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

As noted especially in relation to Priority 2, we emphasise the need for greater clarity and better consistency across organisations around data sharing and linkage for research and public health purposes. We would welcome the NDG's active intervention in this area to bring together stakeholders and ensure that the benefits to society of these data uses can be realised.

14. Are there any priorities you would remove or change?

As noted above:

(a) We would express Priority 2 in wider terms around using patient data in research and public health improvement, not limited to technological innovation.

(b) Priority 4 as described in the document focusses on quite narrow legal issues, which although important are not obvious priorities for the NDG's efforts.

15. Please provide any other comments or feedback to the NDG and her team.

No other comments.