

29.03.19

Office of the National Data Guardian  
1 Trevelyan Square  
Leeds  
LS1 6AE

Dear Sir/Madam,

We appreciate the opportunity to feed into the consultation on different areas of priority by the National Data Guardian.

We have provided a detailed response to the consultation questions below, however it may be useful for me to first outline the role of the GMC. The GMC is an independent organisation that helps to protect patients and improve medical education and practice across the UK.

- We decide which doctors are qualified to work here and we oversee UK medical education and training.
- We set the standards that doctors need to follow, and make sure that they continue to meet these standards throughout their careers.
- We take action to prevent a doctor from putting the safety of patients, or the public's confidence in doctors, at risk.

Every patient should receive a high standard of care. Our role is to help achieve that by working closely with doctors, their employers and patients, to make sure that the trust patients have in their doctors is fully justified.

Our confidentiality guidance for doctors emphasises the importance of trust in the doctor-patient relationship. Without it, patients may withhold information from their doctors, or even choose not to access health services at all. It is for these reasons that confidential medical care has long been recognised by the courts as being in the public interest, and our guidance reflects that.

There are of course important uses of patient information that are not connected to the delivery of health or social care, but which serve wider purposes, and we recognise that in our guidance. But it is vital that policy initiatives for using patient data do not threaten the long standing ethical principles of confidentiality, or undermine the ability of doctors to exercise their professional judgment and act in partnership with patients, respecting their rights to privacy and dignity. We

therefore welcome and support the National Data Guardian being placed on a statutory footing to help ensure that the public can trust that health and care information is securely safeguarded and used appropriately.

We believe that all four areas of priority identified by the NDG are significant, however we recognise that the NDG may need to prioritise within these areas of importance. On that basis we have suggested a lexical ordering amongst the four priorities listed and have provided comments on them in turn.

#### **Priority 4 Safeguarding a Confidential Health and Care System**

We believe that safeguarding a confidential health and care system should be the utmost priority of the NDG and one which remains continually reinforced and upheld.

##### **Area of interest**

***Clarifying the interplay between the requirements of common law and data protection law with an aim of finding a way to explain this that clinicians and patients can understand.***

Since the introduction of the GDPR and the DPA 2018 we have received a number of enquiries seeking clarification between the interplay of the common law and data protection requirements. We have sought to address this in the legal annex of our confidentiality guidance (which we updated in May 2018) – particularly in relation to the concept of ‘implied consent’ – but it is a complex and evolving area.

We therefore welcome and support the recommendation by the NDG to clarify the interplay between the requirements of common law and data protection law, to find a way to explain this that clinicians and patients can understand.

***Progressing the concept of reasonable expectations as an important aspect to shape the boundaries of information sharing.***

We support and will watch with interest the continued work to progress the concept of ‘reasonable expectations’. During the revision of our confidentiality ethical guidance in 2015-16, ‘implied consent’ was one of the issues that was raised regularly. The majority of respondents to our consultation agreed that our guidance sets out a sensible and practical approach to balancing patients’ confidentiality and privacy rights against the need for a workable regime for information sharing. However some respondents expressed reservations about whether making information ‘readily available’ to patients about how their information is used is sufficient for a reasonable inference about their wishes to be drawn. There was also some uncertainty about the boundaries of the healthcare team for the purposes of sharing information for direct care.

Our advice can be found at paragraphs 26-29 of the Confidentiality Guidance.

We say that;

*Appropriate information sharing is an essential part of the provision of safe and effective care. Most doctors work as part of healthcare teams, and doctors and other practitioners need access to relevant, accurate and up-to-date information about patients to enable the provision of safe and effective care.*

*For the most part patients understand and expect that this will happen and we therefore advise doctors that they can rely on implied consent for information about patients to be appropriately shared within the direct care team as long as:*

- *Information is being shared to provide or support a patient's direct care.*
- *Information is made readily available to patients explaining how their information will be shared, and that they have the right to object.*
- *Patient objections are respected, unless disclosure would be justified in the public interest. If safe care cannot be provided unless the information is shared, that should be explained to the patient.*
- *Anyone to whom information is disclosed understands that it is given in confidence, and that they are bound by the legal duty of confidence.*

*We advise doctors that if they think a patient would be surprised to learn about how the doctor is accessing or disclosing their personal information, that they should ask for explicit consent unless it's not practicable to do so (which is explained at paragraph 14).*

## **Priority 2 Using Patient Data in Innovation: A Dialogue with the Public**

We also agree that the use of patient data in innovation should be a top priority.

We know that advances in technology have the potential to significantly enhance the provision of healthcare. As many of these technologies are data driven, in order for this potential to be realised, patients need to understand and consent to the way in which their data will be used.

***How do patients want and expect data about them to be used within health technology? Is there understood to be a reciprocal relationship, whereby those receiving care allow data usage to facilitate improvements? What are the boundaries that people would put around this?***

***How far do public expectations of data usage match reality, for instance in NHS apps and non-NHS health apps? What should be done to ensure expectation and reality are brought closer together?***

We note NDG's concern that dialogue with the public on the use of data has not kept pace with the capacity of technology, resulting in a gap between public expectations and how it is being used in reality. Whilst research has been conducted to explore public views on the use of patient data to enable data-driven technologies, patient expectations will be based on a number of variables and there's no authoritative body of opinion or voice on patient expectations relating to the range of emerging technologies and how they are used in healthcare innovation. NDG could play a key role in raising patient awareness of the challenges presented by data-driven technologies, and building and communicating a body of patient opinion on these issues to inform policy making and innovation, ultimately, building patient engagement, confidence and trust.

Given that the NDG now has statutory footing, it has an influential voice in ensuring that patient data is used appropriately, proportionality and in line with public expectations. There is a lack of clarity on patient expectations relating to how their data should be used to fuel data driven technologies. We see the NDG as having a key role in establishing this clarity and working with the government to ensure that its current relevant standards and any further standards in development are aligned with this.

### **Priority 1: Encouraging Access and Control: Individuals and their Health and Care Data**

#### ***Encouraging greater /easier access for patients to see their health and care records and who has viewed them***

Giving people access and control of health and care data is an important priority. We would want to ensure that in aiding patients to see and understand how their data has been used appropriate safe guards are built in. In our guidance we state patients have a right to access their own health records (see paragraph 131 in Confidentiality) and that doctors should respect, and help patients to exercise their legal rights to do so.

We would also like to highlight some particular concerns about children and young people. We say young people with capacity have the legal right to access their own health records and can allow or prevent access by others, including their parents. However, there is no bright line between childhood and adulthood and a child might achieve capacity at different stages. We do add that in most instances doctors should usually let children access their own health records (see paragraph 53 in our 0-18 guidance) but we are aware that health services can find it challenging to operationalise this in practice. Additional guidance and support from the NDG would therefore be welcome.

### **Priority 3 – Getting the Basics Right: Information Sharing for Individual Care**

#### ***Encouraging better sharing for individual care across boundaries, particularly between health and social care***

We understand the value of joined up care between providers of both health and social care and share the NDG's aim of enabling appropriate data sharing between the two. Our ethical guidance makes reference to both sources of care. We acknowledge that doctors' roles are continuing to evolve and change and that it is likely to be more challenging to make sure there is a legal and ethical basis for using patient information in this complex health and social care environment (see paragraph 4 in Confidentiality).

Joined up care is of particular importance where safeguarding issues about children and young people are concerned. We have detailed guidance on the principles of safeguarding which we expect doctors to adhere to (see Protecting Children and Young People).

We hope that these comments are useful as the NDG decides on its first priorities under its new statutory structure. We welcome future collaboration on these and many other issues and greatly value the work done by the NDG.

Yours sincerely,

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