medConfidential submission to the Digital Commission Expert Panel consultation

We have intentionally kept this document relatively short, with references to additional material in the solutions section. We are happy to go into further details on any parts where useful and not already provided.

medConfidential is an independent non-partisan organisation campaigning for confidentiality and consent in health and social care, which seeks to ensure that every flow of data into, across and out of the NHS and care system is *consensual, safe, and transparent*.

Founded in January 2013, medConfidential works with patients and medics, service users and care professionals; draws advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy; and believes there need be no conflict between good research, good ethics and good medical care. We also engage with data use across Government, as to the first approximation, the data that institutions of state most want to make copies of is your medical record.

Understanding the effects of digital markets

The best way to understand how your data will be used tomorrow, is to see how it was used yesterday. To borrow a phrase, “follow the data”.

Whether in the private sector or the public, there is no expectation that a data subject (whether acting as a citizen, a consumer, or an innocent bystander caught in digital surveillance) will understand what data is collected, nor how that data is used.

The commercial incentives to duplicity and secrecy are strong. What is normal practice in business is unacceptable in the public sector.

What must change is the norm that an individual can not know how their data is used - most people will never look, but that there is secrecy breeds harmful practices because people can’ t see.

The public sector is in a strong place to lead on such issues, and indeed, the Cabinet Office’s Technology Code of Practice (points 6 and 10) contain some indications in that direction - that there should be audit trails, and individuals should know how data about them is used.

After large missteps in 2014, the NHS is slowly moving towards telling patients how data about them is used, and what the effects of their dissent choices are. Where the NHS leads, the rest of the public sector will have to follow - either willingly or as a result of more (and inevitable) data catastrophes.

If all a data subject hears about data use is the ongoing steady flow of failures, there can not be institutional trust in the long term.

Policy and implementation solutions

AI and algorithms in the public sector: For all bodies subject to judicial review, any AI or algorithm involved in input to that decision must satisfy the explainability requirements of judicial review. Should there be a clear public sector mandate that algorithms will only be used if they satisfy existing legal obligations, and that technology tools will need to be procured to satisfy those tools, that will create an international market in which the UK is possibly uniquely placed to lead, if leadership is desired. The UK has the rare combination of an ecosystem of technology companies, a large community of lawyers/judges with a deep and practical understanding of the rule of law, and a public sector open to new tools where they satisfy well known existing legal requirements,

Procurement incentives for competitive markets: Where an NHS body wishes to procure an AI to assist in diagnosis, it should be required to procure 3 - effectively requiring 3 diverse analyses rather than one, replicating the medical norm of a 'second opinion' from a human doctor. That may be extensible to other public bodies.

Data available to life sciences and research: For there to be public confidence in data use, every patient should be able to know how the NHS and others use data about them, and how their wishes are respected. The NHS has established clear processes for the use of data for legitimate research – these do not need to be changed. However, the implementation of the National Data Opt-out remains hamstrung by legacy data disseminations.

This, the first spending review since the 2018 Data Protection Act, allows for a clearer formulation when communicating with the public: "If you want your data to be used for research and for other purposes beyond your care, it will be; if you don't, it won't." (Any exceptions being solely decided by the explicit approval of the Confidentiality Advisory Group – which was placed on a statutory footing in 2014, yet still has no Regulations governing its work.) Past and current heavy reliance on (DPA98) 'anonymous' data as the basis for dissemination both undermines public confidence and limits the data available to research.

The spending review offers an opportunity to reconsider that failed approach, improving public confidence and making more high quality data available to researchers and the life sciences – both underpinned by a commitment that whatever a patient wishes, they will be able to see how their wishes were respected. Any suggestion of 'data trusts' for NHS patients' data requires as a prerequisite the admission that the NHS itself will never get data dissemination right in patient's interests. Public confidence in data for life sciences and research would be higher if the message was clear, simple, and accurate: *If you want us to use your data in legitimate projects, we will; if you don't, we won't.*

Technology in the NHS: Clinicians will use technology when it helps them with patients; when it doesn't, they don't – no matter how hard NHS England may push it. The FHIR (Fast

Healthcare Interoperability Resources) standard is now internationally recognised as the standard for interoperability between health systems – yet the first version was only published *after* the last spending round. Treasury / DH / NHSE should ensure that companies cannot use contracts to limit or prohibit interoperability, or to require bulk data copying from core hospital systems into commercial companies. Where they are proposing new national programmes, chopped up into parts, what happens at the boundaries between parts?

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