Consultation response: 10 Year Health Plan for England

2 December 2024

Introduction

In November 2024 the UK Government requested submissions “to hear people's views, experiences and ideas as part of this engagement to help shape the 10 Year Health Plan for England”.

We noted the invitation to contribute to the review by 5pm, Monday 2 December 2024.

This is a significant opportunity and of interest to Members of use MY data. The Secretariat sought the views of Members of use MY data and their direct views have been collated into this summary response.

The response has been submitted directly using the online web form. The contents of our submitted review are also shown in this document below, to make it more readily accessible and referenceable to our Members and other readers.

Responses on the five questions in the consultation

We have listed each of the five questions in the consultation below, together with the our composite response comprising what we heard use MY data Members (shown below each question in blue).

Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

We are the only UK independent movement of patients, relatives and carers who want to see patient data used for the benefit of patients and the NHS. We are unique.

As a data-focused movement, we have commented primarily on data issues. However, if the NHS is to develop as we all want, the data issues are absolutely critical to get right.

Firstly, we would like to express our wish that the Government's analogue to digital objectives are 'SMART' in nature. i.e. Specific, Measurable, Achievable (which should include indicative funding over 10 years), Relevant and Time bound. i.e. milestones.

We want to see:

- Access to our own, comprehensive, health records so that we can play an active part in our own care
- A step-change in transparency about how our health data is used for our own benefit, for the benefit of others, and to help the NHS deliver
- Secure, timely, managed and audited access to health data for research, underpinned by end-to-end transparency, and with patients on all data access groups and decision-making panels
- A shift in the balance of perceived risk, to ensure potential benefits play a much more prominent role in data access

Our view is that to achieve this the Government will have to empower NHS England to mandate a lot of what is currently delegated to individual GP surgeries and hospital trusts.

Without initiating major organisational change (which no one wants) there is going to have to be a lot of 'top down' while still leaving room for innovation at GP or Trust level.

In undertaking this, we emphasis our core principle about the use of patient data, that the transition needs to be marked by openness and transparency about who is doing it, what they are doing, and what data they are handling (if any).

Shift 1: moving more care from hospitals to communities

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

As a movement focused on the beneficial uses of patient data, to treat us and to help others, our Members have long recognised the need for a single healthcare record, that patients themselves can see.

For too many years, the lack of comprehensive, interoperable data-communications between primary and secondary care data has long been in need of addressing.

Patients have heard that they “can see your own health data”, but the reality is that this only applies to your own GP record, and in fact only parts of that record. Patients with any level of complexity of care over time simply cannot see what they need – a full view of their health record, irrespective of where parts of that record were created or stored.

Not only is this not in the interests of patients, it has contributed to the growing levels of distrust in parts of the public about how our health data is used, with comments such as “if there’s nothing to hide, then why is it being hidden from me!”

We want to see our social care data as being part of our overall health record. The current track record of non-delivery of a singular view of our primary and hospital data does not bode well for the further inclusion of wider social care data. A significantly different approach and conversation is needed – one which includes patients as part of that conversation.

The benefits of a singular view of our own data would not just be to patients, but would, as emphasised in the recent Sudlow Review, be a major benefit to research and to the NHS. But these benefits, for patient and for research, have not been realised because our data remains fragmented.

The NHS will move towards more tests, scans, treatments and therapies being undertaken nearer to where people live, including places like GP clinics, pharmacies, local health centres, and in people’s homes. It is essential that this data becomes part of the health record.

Shift 2: Analogue to Digital

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

History does not serve us well here, and we must recognise that previous attempts to bring our health data together nationally have failed and have seriously damaged trust. It is absolutely critical that this is not repeated. In our view, these national data programmes have failed because they have been seen as technology projects. They are not. They should be seen as communications and engagement projects, with technical deliverables. We have a unique opportunity to address this.

As the only patient movement with a focus on patient data, we would like to highlight some technical aspects which must be addressed, if we are to see a positive move towards digital. Briefly these are:

- Data controller regulations/responsibilities – the evident over-emphasis on “guardianship” must be rebalanced with an increased emphasis on “enablement”. If data is kept in a locked box, it can be guaranteed to be safe, but no good will come of it.
- Mandation of data standards – whilst the NHS has had data standards for many years, these have often been ignored or not misinterpreted. If we want consistency of data, high data quality and wider uses, standards are critical
- Mandation of software interoperability – the lack of interoperability of software has held the NHS back for many years. The NHS needs to follow the lead from other industries who have managed to adopt strict industry-wide interoperability standards, even in competitive business areas
- Driving technical convergence - without a comprehensive target data model across the NHS/social care, we will never achieve interoperability and a National Health Record. Developing such a model has to be one of the starting points, and we must make sure organisations adopt this model.

- Strict cyber security plans - a comprehensive communications plan is needed to reassure patients on confidentiality issues and to point out the benefits of research using anonymised patient data
- Communications and engagement – the largely negative position which can appear in the media, such as the dislike of 'big pharma' which is so often expressed, can only be addressed if we communicate to patients and the public the reality, including the benefits that groups such as ‘big pharma’ have brought, and can bring
- The non-digitally-active - we do recognise that NHS England is still going to have to cater for the non-digital, or less digitally-active patient, of which there are many. In designing new systems, such patients need to be catered for. e.g. GP surgeries to continue to offer telephone and walk in queries/appointments booking, viewing of records; etc.

Shift 3: Sickness to Prevention

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Patient data can play a key role here, both in understanding late diagnosis and in helping with decision support on identifying illness at an earlier stage.

Recently, the Sudlow Report highlighted that data from screening services is not routinely linked to hospital diagnostic/incident data. This has to be a basic function of any population screening programme. Without such linkage and insight, which would identify “interval cancers”, it is simply not possible to evaluate whether screening is working effectively. The solution is not technically complex, nor costly. It is about prioritisation and changing behaviours of data controllers.

Some years ago, the NHS developed a world-leading cancer data analytics programme called Routes to Diagnosis.

Cancer Research UK (CRUK) says that the UK has poorer survival rates for cancer than other developed countries, in part due to the stage at which cancer is diagnosed. In 2018, 45.5% of cancer cases in England were diagnosed at stage 3 or 4 (note, all these statistics come from patient data). The Routes to Diagnosis programme linked data from secondary care and screening settings, and mapped every single new cancer diagnosis back to its point of entry. That’s when we first understood that 25% of all new cancer diagnoses were via an emergency admission, and that those patients had a massively poorer prognosis. As a result, clinical and pathway changes were made, and that figure has dropped to around 20%, saving lives.

However, that programme has never been able to look further at “why” people arrive as an emergency with cancer. That insight lies in primary care data, which has so far not been linked. We believe that this lack of patient data usage is costing the lives of cancer patients.

If we were to extrapolate this position to other disease areas, it quickly becomes clear that whilst “data saves lives”, not using data is costing lives.

Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

- **Quick to do, that is in the next year or so**
- **In the middle, that is in the next 2 to 5 years**
- **Long term change, that will take more than 5 years**

Quick to do:

- Linked screening and incident data
- Underwriting liability of GPs sharing data, nationally
- Patients on every data access committee
- Publication of mandatory data transparency standards
- Commitment to every patient having a singular view of all their health data
- The start of a clear, long-term, data-dialogue with the public

2 to 5 years:

- Timelines agreed and published for singular view of your own health data
- Secure Data Environments become the norm, replacing the need for data release
- Data releases, done under exception, publicly reported under a new transparency framework
- Data access delays removed, with a new integrated application and access process for researchers
- Data transparency standards implemented across NHS and academia

More than 5 years:

- Patients have access to their full patient record, including details of where their data (either identifiable, pseudonymised or anonymised has been used)

* use MY data

The only independent UK movement of patients, relatives and carers focussed on the use of patient data to save lives and improve outcomes

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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.

Our mission statement

- **use MY data** is a movement of patients, carers and relatives.

- **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** 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** 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.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.

- We work to bring a patient voice to all conversations about patient data.

- We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available here.

- 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 events for patients and the public, focussing on patient data topics
  - a library of resources of data security, consent
  - narratives from individuals about the value of collecting and using patient data.

- 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.

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use MY data is registered as a company limited by guarantee in England and Wales (14425977)