*use MY data

Position statement

GP Data for Planning and Research (GPDPR)

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.

Background

On 12 May 2021 NHS Digital, the national organisation which designs, develops and operates the national IT and data services for the NHS in England, announced the introduction of a new service, “which will more efficiently collect primary care data and make it available for better planning of healthcare services and for use in medical research.”

This new service, called General Practice Data for Planning & Research (GPDPR) will begin to collect data from all GP Practices in England into NHS Digital from 1st July 2021. This extends the use of data beyond the pandemic response, where data was used for purposes such as identifying people who should have priority for vaccinations because of underlying health conditions.

NHS Digital has made the following statement:

“NHS Digital has been legally directed by the Secretary of State for Health and Social Care to establish a new strategic system to collect and provide access to near-real-time data from GP Practices for planning and research purposes.”

“NHS Digital is committed to complete transparency with patients and the public about the collection and use of health data. We will continue to publish detailed information about our data policies, protocols and systems and we will continue to publish details of all data we share via our data release register.”

What benefits are anticipated by NHS Digital?

The following text which describes some anticipated benefits has been extracted from the NHS Digital website:

“As we emerge from the pandemic, but into an era of enormous demand for NHS services, data will continue to be a critical asset in planning services and facilitating research into conditions such as long COVID. Therefore, NHS Digital has been legally directed by the Secretary of State for Health and Social Care to establish a new strategic system to collect and provide access to near-real-time data from GP Practices for planning and research purposes.”

“The new system will improve efficiency in data collection from GP practices, and significantly increase the speed and efficiency of providing appropriate access to that data, reducing the burden on GPs. Patients can have greater confidence that their data is being used in ways which preserve their confidentiality, as a result of the rigorous, standardised and unified approach to data management and access.”

The Chief Executive of NHS Digital, Sarah Wilkinson, said:

“General Practice data is particularly rich and valuable because many illnesses are treated predominantly in primary care. We want to ensure that this data is made available for use in planning NHS services and in clinical research, but it is critical that we do this in such a way that patient confidentiality and trust is prioritised and never compromised.”

NHS Digital website,

https://digital.nhs.uk/news-and-events/latest-news/improved-collection-of-gp-data-launched

https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/advice-for-the-public

This Position Statement from use MY data describes the areas which we consider to be essential elements of the NHS Digital commitment to transparency.

1. The benefits of uses for research and planning need to be highlighted

As a movement, use MY data wants to see the benefits of using data to improve patient care and outcomes. There needs to be a much greater focus on explaining the anticipated benefits of the data usage, in ways which are understandable and accessible. The NHS relies on both effective planning and innovative research to develop and deliver its services, and improve treatments, health results and the service for patients. This needs to be highlighted much more.

We strongly encourage the use of real-world examples of positive uses, both for planning and research, describing how this has benefitted patients.

2. Our principles of transparency should be adopted

Transparency should underpin everything and is essential if the trust and support of patients and the public is to be maintained and developed.

Transparency means operating in such a way that it is easy and obvious for others to see what actions are performed and how. In a nutshell – **Say what you do, do what you say**.

Our guiding principles for transparency should apply to the GPDPR programme:

Accessible -	there needs to be easy access to information about GPDPR which is available through a variety of routes, including online and hard copy through (for instance) GP Practices
Understandable -	communications need to use language that the public will understand
Relevant -	the information provided must address audience concerns directly and should be updated as new concerns are raised and addressed
Useable -	information needs to be in a form that meets the audience needs
Assessable -	information must provide sufficient detail, including how to find out more

3. **A robust communications plan should be undertaken**

   Clear communications are essential if public trust is to be gained.

   This should include being clear about what data is extracted, what data isn’t extracted, the intended uses of this data and the anticipated benefits of this usage.

   The plan needs to demonstrate how patients and the public are being made aware of this, including proactive communications which focus on purpose, safeguards, where to find more, and what options people have. It is not sufficient just to place this on a website and expect people to know that it exists.

   There needs to be clarity about what choices patients will have after the collection has started, and what happens to historic data which has already been collected, if the patient chooses to opt-out at a later date.

4. **Governance, safeguards and reporting**

   There must be defined management of access to the GPDPR data to ensure that only approved users are able to access the data and it is used to benefit the public.

   The approval process, and the role of patients in this process, should be clear and published, as should the results of any application, whether successful or not.

   Additionally, the GPDPR data should only be used for approved purposes so that, for instance, it is never used for marketing or insurance purposes and also the NHS or Government must share fairly in any revenues generated.

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

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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 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.