



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

## **Realising the benefits of a truly National Health Record**

**use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care and well-being for all.

**use MY data** supports and promotes the protection of individual choice and privacy in the sharing of healthcare data to improve patient treatments, outcomes and experience.

**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 design and improvement, and in research, aimed at improving clinically informed patient decision making, treatment and experience.

### **Overview**

Currently if you are taken ill and go to a hospital away from home, that hospital may not be able to see your health records when making potentially life-saving decisions about the care you should receive. In many areas, even your local hospitals may not be able to see your GP record in an emergency. **use MY data** believes these data limitations can and should be overcome as a key step in delivering the best care or service wherever you need it.

**use MY data** supports a move to ensure all parts of your health and social care record are available and accessible to you and your health professionals across the UK when you need treatment or advice.

### **Why does use MY data support this change?**

We support this because, in making the best decisions about what advice or treatment to give you, clinicians need to know your full health background - your health history, your current health problems, treatments, medications and your allergies. In fact, they should be able to access all the data held by your GP, hospitals and mental health and social care providers that have previously treated you.

This use of your data, to provide you with the most appropriate healthcare, is the key reason why **use MY data** supports this change but there are two other important benefits that this access to health records will enable.

- Personal access to your own health record. Through full security controls, you should be able to access your health records to better understand the trends in your health and potentially to add health data such as daily blood pressure readings, to enable professional monitoring of your progress. Also, to check if any health incidents are missing and if there are any errors on your health record which you can then ensure are corrected.
- Once this data is available nationally it could enable a separate, free-standing anonymised version of the data to allow approved researchers to carry out strictly controlled research in order to identify better approaches to prevention and diagnosis, to support smarter and more personalised treatments and to promote well-being and good health.

## **Some practices and principles which we would expect service and care providers to publicly adopt**

### **Total security**

Currently health records are spread between GPs, hospitals and other care providers and these organisations have varying levels of data security expertise and there are differences in the data security standards that they use.

The integration of health records across the country will allow the highest standards of data and cyber security to be implemented and supervised by experts accountable to the NHS and to the public.

As any breach of security or data management could compromise the records and affect patients, so it is essential that the highest level of security standards and expertise are applied in the creation and management of this national resource. This must be regularly and independently verified, and the results of such audits must be made public.

### **Individual Choice**

All patient choices about how their data may be used must be fully respected. This includes, for instance, the National Data Opt-out\* and any other patient-choice mechanisms that healthcare organisations have adopted. \*NDOO is England only

There must be a clear description of how the wishes of patients regarding uses of their data are respected.

### **A UK wide approach**

The benefits described above will be magnified if the health records could be shared across the four devolved nations of the UK and available wherever you need treatment. That should be the goal.

However, there are differing starting points and some differences in legislation and the way patients can express their preferences for usage of their data.

In the interests of early realisation of the benefits it may be expedient for the UK nations to make initial steps independently, but plans should be created for eventual convergence to deliver the maximum health benefits for all.

### **Implementation**

There needs to be a clear national strategy and plan to ensure that this happens by a given date, recognising that some organisations holding patient data will find it harder than others to make the necessary changes. All investments in new technology need to reflect the national plan.

## **Secondary uses of the data**

Whilst the main aim of the move to a National Health Care Record is to provide better information to doctors, nurses and other health care professional at the point where patients need their help, there will be another benefit in the creation of a separate data environment containing anonymised data, which will support research and planning. This will be the widest and deepest health information database in the world.

There must be strict controls over access to such a database to ensure that only approved researchers are able to access the data for approved research. It should never be used for marketing or insurance purposes. The NHS or Government must share fairly in any revenues generated by the use of our data.

## **How our Members should adopt and use this statement**

- Support the sharing of a health records for care
- Feedback to the Secretariat any concerns you may have or any concerns that organisations you interact with may have
- If you need advice on taking this forward, contact the Secretariat and we will either help you directly, or put you in touch with another Member who can help

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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.

## About use MY data

- **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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