

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

CALL TO ACTION - My access to my health records

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.

At our March 2021 webinar *Show me my data!* we explored the topic of patients being able to see, interact and even make corrections to their own health records. The webinar highlighted the reality about patient accessible, and/or patient-held records, across the UK, together with the constraints, blockers and enablers.

Following the webinar, we polled the delegates to ascertain their priorities for next steps for use MY data to take. This document is a summary of those next steps, in the form of a Call to Action.

A Call to Action

Currently English GPs are required to give their patients online access to their own GP records if the patient requests this access.

use MY data became concerned that this was perhaps not well known to patients and not always working well in practice. We held an online workshop for our members on 3 March 2021 to brief members on this service and to understand whether patients valued this access and what concerns they had.

We also examined with patients whether this access should be extended to include data held in hospitals, and not just GP Practices.

As a result of feedback from those who attended the workshop, use MY data has prepared this Call for Action. There are two main themes:

- a) The NHS should provide better information for GP Practices and patients about the rights of patients to see our own record and how we can overcome any problems in that access,
- b) The NHS should extend this right so that patients can access our hospital data too.

Benefits of online access to our records

The feedback from the majority of participants was that they valued the intent of being able to access their health records and, in particular, they appreciated the opportunities:

- To look back and reflect on information discussed with their GP during consultations
- To identify trends over time on results such as blood tests as a prompt to their taking action
- To identify missing or incorrect information and have the record corrected
- To be able to access health care records when needing treatment in other parts of the country or even overseas (for example via an app or a portal) so that those doctors can see our GP Record and make better informed care decisions in possibly life-threatening circumstances.

Some patients have some concerns about online access to their records

Attendees at the workshop did express some concerns about access:

- Will the data be secure, or can unauthorised people access the data and, in accessing their own data, will patients leave a digital footprint which might be misused?
- This has been Government policy for several years. Why has progress been so slow?
- Do patients have access to the full GP record including free text and hospital letters?
- How can I persuade my GP to let me have access to my record?
- How can patients ensure errors are corrected?
- What about access to older information such as childhood vaccinations?
- GPs seem to use the fact that family members and carers are referred to in my record as a reason for not allowing access. What's the position?
- If patient access can be done for GP records, then what about hospital records?

The use MY data Call to Action for the NHS

On the basis of what use MY data learnt from the workshop and from other patient discussions, use MY data calls on the NHS to take actions to ensure that:

1. All GPs are aware of their **duty to make records available** to their patients via the online service, that they know how to do this, how to overcome any problems and they know how to deal with any potentially confidential references to third parties.
2. **Better information** is created and widely distributed to patients to ensure they know their rights of access, they know how to initiate the service, what to do if their GP does not cooperate in providing this access, how to overcome any technical problems, what information they can expect to see and what information can be legitimately withheld and what to do if they observe missing or incorrect data.
3. There is a **plan for improvement** in the service to include more effective access to the GP record.
4. All these principles are applied in order to allow **patient access to hospital records**.

The use MY data Call to Action for patients

In keeping with the themes above:

1. Ask your GP surgery to ensure that information about how to access your records is displayed clearly in the surgery and on the surgery website.
2. Ask for access to your own records (if you wish to do so) and ask for any errors or gaps to be corrected or completed.

Annex: Access to your health records in the UK

England: How to access your health records

<https://www.nhs.uk/using-the-nhs/about-the-nhs/how-to-access-your-health-records/>

Northern Ireland: Accessing medical or Health and Social Care records

<https://www.nidirect.gov.uk/articles/accessing-medical-or-health-and-social-care-records>

Scotland: How to See Your Health Records

<https://www.nhsinform.scot/publications/how-to-see-your-health-records-leaflet>

Wales: Accessing your Medical Health Records

<https://thepracticeofhealth.nhs.wales/>

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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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