

## What if the NHS Constitution was rewritten to have as much emphasis on patient responsibilities as patient rights?

The NHS Constitution for England sets out the objectives of the NHS, the rights and responsibilities of the various parties involved in health care (including patients, staff and Trust boards) and the guiding principles which govern the Service.

These principles are clearly stated and well understood. The Constitution's sub-title is "the NHS belongs to us all" and few would dispute that. And because the NHS belongs to us all, we have a responsibility towards it, as much as it has a responsibility towards us.



The current Constitution is largely written for the benefit of patients, quite rightly so. It describes what each of us should expect from the NHS; our NHS. As well as detailing patient rights, it includes some responsibilities for patients themselves, which are largely around helping the NHS to function for patient benefit.

On closer inspection, patients and the public have thirty five legal rights and only nine responsibilities.



This feels somewhat of an imbalance, particularly when the relative strength of the wording of the rights is much more forceful than the wording used to describe the responsibilities.

So what about redressing the balance? What would this mean? What would be the benefits in strengthening and clarifying the responsibilities of each of us to our NHS, and how might this help the NHS work better for all of us?

One example of how the imbalance might be addressed is to implement a responsibility for patients to allow their healthcare data to be used to improve treatment for other patients, present and future.

A basic facet of human history is that all our insight, all our gained knowledge, all our developments are based on learning from experience, whether that be for a new drug, a new intervention, or a new surgical procedure. And all experience of learning is based on data.

The importance of using data is not lost on patients who have been through treatment. Margaret is not alone in being grateful for the information given by previous patients, which made her treatment less radical and more effective.

**“My experience of cancer was obviously made a lot better by the fact thousands and thousands of people have given willingly of their data so that all the research could be done. So, instead of having radical mastectomies as was happening a hundred years ago, my cancer was dealt with relatively painlessly.”**



So if it makes sense for all patients' healthcare data to be automatically pooled and then used for the benefit of other patients, why is this not already part of the Constitution and what are the downsides?

For data, the most obvious issue is patient choice. Whilst most patients support the secondary use of their NHS data, some do not. Making patient data use a condition of patient treatment would fundamentally change patient choice. It could mean some people refusing treatment and nobody wants that.

But that choice itself is complex. Given the clinical time constraints, is it actually possible to explain to someone all the secondary uses of their data, the potential risks and the major benefits that can be accrued for such data usage? And if it is not possible to explain, how can any patient make a truly informed choice?

In other scenarios we tend to accept complex terms and conditions on trust, on the basis that we will get something in return.

We simply click through on our iTunes accounts, our loyalty cards and our free internet usage on the basis that we want to use the service and that we accept/believe that the service for us will be improved as a result of our data being used.



Commercial companies, such as supermarkets, know the real value of customer data and how to use it, and they know what their customers want in return; discount coupons, offers and benefits.

Would it be possible to follow this model for the NHS Constitution and demonstrate the better treatments and outcomes that have been achieved by using patient data?

One way to highlight the benefits would be to give patients feedback about how their data are used, for example information about research that has used their data, the results of the research and how this has improved treatment and outcomes for patients.

In the words of another Margaret, another cancer patient:

**“I believe that as a patient I have a responsibility to the rest of society in permitting my data to be used, but I also have the right to ask clinicians and researchers, or perhaps rather demand, that my data is used, remove the barriers, use for purposes of audit, comparison, research, ask questions and find answers for me and all the other patients like me.”**



The recent report from the National Data Guardian highlights the complexities of data usage and the need for a reasoned debate about what is in the public interest and indeed what is meant by “public interest”. Societal views about the relative sensitivity of different types of data change through time.

Difficult areas such as this are always about balance; balancing risks and benefits, balancing choice with the overriding public interest, balancing rights with responsibilities. If the NHS Constitution had this balance, perhaps it might better reflect not just what the NHS should do for us, but what we should do for the NHS.