

1. Data Usage Reporting

Whatever your data, whether it is your medical records, your DVLA record or your bank statement, you should know who has looked at those records, and have a good idea as to why.

Whether you have opted out of care.data, or are captured by default, there are a whole host of other data flows that relate both to your direct care and to all the other things that happen around the NHS. You may have a Summary Care Record (SCR), for example, and your hospital (HES) records may – or may not – be sent to various places depending on your consent, where it is applied, and irrespective of your consent where it isn't.

Some of these data flows are routine; for example, the [NHS Business Services Authority](#) sorts out paying prescriptions, so it gets a copy of that data so it can do its statutory job. But if you're treated in a hospital, the various organisations – both public and private – who provide services to that hospital may also get a copy of (some of) your medical record for various reasons.

Why does this matter?

If you don't know where your data has gone, there's no way to know whether your wishes are being respected. And when there is a problem, there's no way to know whether you personally were affected. You may have opted out, but then how will those who do opt out – who, almost by definition, will have lower trust in the system than others – be able to know that their wishes have been respected? With the constant drip, drip of bad news about data, what will begin to assuage those concerns?

Most Summary Care Records, for example, will not be accessed or viewed when they shouldn't have been – but without you knowing when your SCR was accessed and by which organisation, you have no way to know whether or not your confidential details have been protected. NHS bodies have that information, and can tell the Health and Social Care Information Centre (HSCIC).

Since the data debacle that came to light in early 2014, HSCIC has undertaken a process of significant internal procedural change. This change is ongoing, but whereas in March 2014 the Information Centre couldn't say to whom it had sent data that month, shortly it should be possible for HSCIC to tell each individual patient exactly where their medical record went, and why – both for their direct care and for the variety of other uses around the system. And, in the coming months and years, for each individual's consent choices to be honoured system-wide within these data flows.

With regard to specific uses of data there is, for example, a broad base of support for ethically-approved medical research. The UK wins more than its fair share of Nobel prizes and other measures of esteem, not to mention the development of new treatments to help all. As a patient, your medical records will have been used in a variety of these studies over past decades, but until things began to change quite recently there has been no way for you – as a patient who contributed their data to this research – to receive the knowledge of the outcome of these research programmes, even though many years may have passed since your records were used.

HSCIC should remember, and can tell you. Academics and researchers are already required to tell their funders (and hence the public) of the outcomes of their research, in academic papers or other published outputs – so if they tell HSCIC, then HSCIC can tell you about the projects in which your data was involved, however small or large its contribution.

A 'data usage report' that covers all uses – both for direct care and for secondary use – means you won't merely have to trust that your data was treated properly by the NHS. You can read your report, and know for yourself.

There are some parts of the health and care system that won't and shouldn't ask for NHS numbers, such as some services relating to sexual health, so these will not be included in the report – but if your NHS number is used, then it should be included.

If there are good reasons why something shouldn't be included in the data usage report, [as the law recognises](#), then maybe the NHS number shouldn't be used. If data *can* be linked then it likely *will* be linked at some point, and if this shouldn't happen then it may be best to use measures that tend to impede linkage – such as not using the NHS number.

Why is a data usage report so important?

Data 'wants' to be copied. Without a full commitment to individuals knowing where their data goes, and what for – which must be for everyone, not just those who don't choose to opt out – mistakes caused by secrecy will continue to happen, with potentially catastrophic effects on public trust in the handling of NHS patients' data.

What might a data usage report look like?

In autumn 2014, medConfidential produced a mock-up example of a [personalised data usage report](#). We understand that discussions have moved on since then, and that some of the sections may be slightly different, but this is an active and ongoing discussion it is vital to have if patients are to have confidence in the handling of their medical records. And, given the NHS has now committed to patient-level transparency, a similar approach could be applied more widely across Government in its use and re-use of our personal data.

For it is only with data usage reports, available on demand to every citizen, that initiatives involving '[Bulk Personal Datasets](#)' can realistically go forwards. Given continued controversy in the NHS over where some patients' data is sent, and on what basis – and the lack of precision in some of the claimed legal safeguards – we simply cannot afford for data usage reports to be mishandled, as so much of the care.data programme has been up to now.

Data usage reports represent an opportunity for NHS bodies and everyone else who'll have access to our most sensitive information to demonstrate they are trustworthy, by providing [what Onora O'Neill describes as "usable evidence"](#) of their competence, honesty and reliability. It's only through trust based in actual knowledge that we can rebuild the confidence essential for a 21st Century NHS and wider care and public services that through consensual, safe and transparent use of data will benefit, and will be seen to benefit, all.

Given the overwhelming need for the uses of medical records to be completely transparent, "personalised data usage reports" can provide a patient-readable report on **Health Accesses for Research and Treatment**, and also the knowledge and benefits gained by such research.