

To share or shaft?

[Peter Singleton](#), Director, Cambridge Health Informatics Limited

The catchphrase of Robert Killroy-Silk, host of ‘Shafted’, a quiz programme in the early 2000s, can be re-purposed to describe a dilemma facing the NHS and healthcare generally.



Do we want to use our data wisely to improve the quality and safety of healthcare or keep it locked in silos where it can't be used, but no-one can be accused of mis-using the data or breaching medical confidentiality?

While this last position plays very much to 'privacy' concerns, it also serves to 'shaft' people by preventing the discovery of better ways of working or detecting and correcting poor practice.

People may suffer unnecessarily or even die because we simply didn't know better – or didn't know better earlier enough.

All the arguments about COVID statistics have shown just how tricky it is to use data well – especially if you haven't worked out what data you need so that it actually being collected at all – or if collected that it is reasonably reliable. However, data collected for one purpose may not work well in another.

PHE collected information about COVID-positive patients and their deaths, which was appropriate when we had no idea how the disease might affect people.

Once we knew some people were asymptomatic, then using this data to present raw mortality rates was clearly inappropriate, but now that we know also that we appear to have 'long COVID' then collecting this data and analysing more than just deaths may well prove a very wise choice indeed.

This is just a case of 'lies, damned lies, and statistics' – especially when mixed with politics. You have to understand the whole process – and, in a Catch-22 situation, if you don't have any data to start with, you probably won't be able to work out what data you will need.

There are more than enough checks on data being used appropriately – the NHS is full of regulators and advisory panels that help make organisations 'accountable' and to double-check that data protection and confidentiality are being respected.

It can take years for researchers to navigate the system and get access to the anonymised data they need to investigate some aspect of healthcare.

Part of the problem is that these panels are all 'independent' which, unfortunately, can mean that they are also somewhat arbitrary and inconsistent as it will depend on the composition of a panel as to what they decide for a particular application.

Researchers have been known to be bounced between approval committees as each requires changes to the research protocol which then has to be re-approved by the others.

It is not always the bedlam that this suggests, but researchers do require persistence and patience.

The good news is that the widely decried GDPR does allow member states (even the UK) to make local 'derogations' about how we will use data.

We could try to grasp the nettle that we do need to use data better (in all sorts of ways) so that we have the infrastructure to support and inform 21st century medicine.

Now may be the time for the Secretary of State to define what we need to do with data across the NHS.

To put this all in context, whenever you dare to take a flight again, would you be happy to know that the pilot was wearing a blindfold so that he couldn't possibly tell anyone that you had been on a jaunt to Majorca – or would you sooner he could actually see what he was doing and read

the instruments (which gather data) to make the right decisions to get you to Majorca (and back) in one piece?

So it is with medicine: we need to have better data use to inform doctors, nurses, clinical teams, care providers, regulators and government departments about what is really happening

– what works and what doesn't.

If you like living dangerously, then you can also choose to opt-out of letting the NHS use your data for 'research and planning' [here](#) - then it will be your choice as to whether to 'share or shaft'.

But make sure you don't get ill or get old!

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