Data sharing in health and social care—how what happens to you helps others

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What is data?

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He was wrong, but he did have a point.

Data is not just about counting things and making big numbers. Sometimes we do wind up with big numbers, but that’s because a lot of people need care every day. In fact, data doesn’t even need to involve numbers at all.
What gets collected and why?
Examples of data use in service improvement
NHS hospital bed numbers: past, present, future

Figure 4: Average number of beds available by category, 1987/8-2016/17

Source: NHS England 2017a

Note: The drop in bed numbers between 2009/10 and 2010/11 is likely to be attributable to a change in data-recording methodology between these years. This means comparisons across the period are subject to some uncertainty.

The rising cost of medicines to the NHS: what’s the story?

Figure 2 Estimated prescribing costs (£ billions) by care setting, 2010/11 to 2016/17

Notes: Primary care prescribing (PFP) refers to products prescribed and dispensed in primary care. Hospital prescribing dispensed in the community (IFPS-HPC) captures all prescriptions written by health professionals in hospital but strictly dispensed in the community. Hospital prescribing dispensed in the hospital pharmacy (IFPS-HPA) captures prescriptions written by health professionals in hospital that are dispensed by a hospital pharmacist.

Source: NHS Digital 2017a
Data less thought of?

As I mentioned earlier, not all data requires numbers—there are many subjective areas where it’s either difficult or impossible to establish a numerical value for an outcome.

Patient experience is usually captured through survey data, gathering patient opinions on various aspects of care into datasets like the inpatient survey or GP patient survey.

These are used less often in media stories, but are an important part of judging the actual experience of care for trusts.

Patient surveys – recognised internationally as a key marker of the quality of care, and an important tool for improvement in the NHS – provide a unique perspective, complementing the wealth of other data on hospital performance gathered by trusts and regulators. Now, for the first time, The King’s Fund and Picker Institute Europe have analysed longitudinal inpatient survey data for acute trusts over a nine-year period (2005 to 2013).

The survey questions that were analysed (20 of a much larger number) were grouped into five aspects of care that matter most to patients: access and waiting; safe, high-quality co-ordinated care; better information, more choice; building better relationships; and a clean, comfortable and friendly place.

Key findings
There’s plenty that’s collected and not published, in particular individual requests made to trusts by CCGs for monitoring purposes, often linked to conditions in contracts. Some trusts feel this is burdensome and sometimes duplicative of effort.

There’s also plenty that’s not collected that you might expect, including:

- Data on the number of GP appointments in England
- Data on the amount of community care provided in England
- Data on the outcomes of patients who receive treatment for non-life threatening illnesses.
The public and their data

The way that data is shared and permissions given when it is obtained have changed significantly over the last 5 years. The care.data “scandal” (really a series of miscommunications) made a lot of people much more sceptical about how their data was used. Since then, the Caldicott Review has made a series of recommendations, including moving from an opt in to an opt out basis for consent to sharing of data for secondary purposes.

There’s still plenty of evidence that the public trusts “the NHS”, but some people are unconvinced that data is used legitimately or safely, with 1.6m people opting out of secondary data use in July.
Integrated care systems and data
Thank you

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