



What is transparency?

'Transparency implies openness, communication and accountability'

'Transparency, rather than targets, will help to improve our healthcare system – and people's trust in the NHS will soar.

By publishing more unbiased data, results in all areas of healthcare will improve, clinicians will work better, and people's trust in the NHS will soar'

Source: Jeremy Hunt, via 'The Guardian' December 2012

'Transparency of outcomes not only saves lives, it is a basic human right. But the NHS cannot answer basic questions about the quality of services it provides such as how many people are receiving chemotherapy and with what outcome. Until we can answer that kind of question routinely and with accuracy, we will not measurably improve patient outcomes.'

Source: Tim Kelsey, via 'The Guardian' March 2013

What do we mean by data protection?

The Data Protection Act (DPA)

Controls how your personal information is used by organisations:

Data Must be.....

- Used fairly and lawfully
- Used for limited, specifically stated purposes
- Used in a way that is adequate, relevant and not excessive
- Accurate
- Kept for no longer than is absolutely necessary
- Handled according to people's data protection rights
- · Kept safe and secure
- Not transferred outside the UK without adequate protection

What do we mean by data protection?

'Every citizen should feel confident that information about their health is securely safeguarded and shared appropriately when that is in their interest. Everyone working in the health and social care system should see information governance as part of their responsibility'

Source: Dame Fiona Caldicott, The Information Governance Review, March 2013

What do patients think? We are all patients I want to know how my GP/Hospital performs. I need transparency I want to know that my data is being used appropriately. I need transparency

What do patients think?

Patients have views and we must respect them:

'The NHS has a terrible record in keeping information confidential and there is a huge risk that patients will start to withhold information from their GPs because they do not believe it will stay private. That could have catastrophic results for care.'

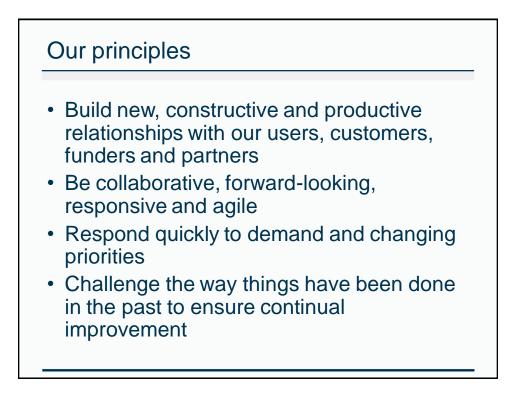
Source: Big Brother Watch, February 2013

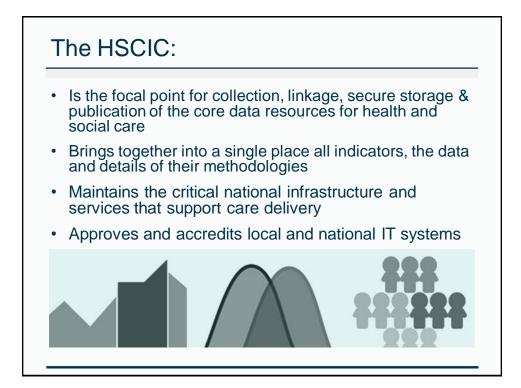
The Secretary of State for Health.... has given a commitment that, for extractions of PCD from GP records that are to be sent to the HSCIC, **patient objections will be respected**

Source: 'Care.Data' Guide for GP Practices, May 2013





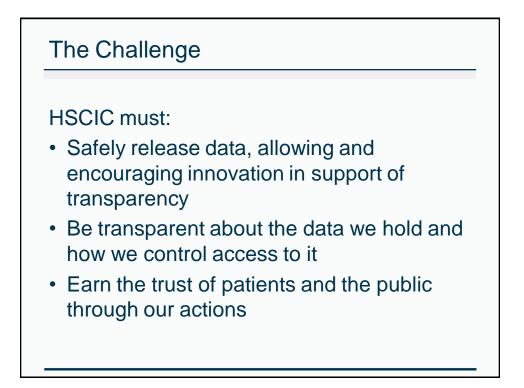








- Practice Level Prescribing Data: Largest ever release of Open Data. Presentation level since September 2012 (10m rows of data per month!)
- Linked Hospital Episode Statistics (HES) to Mental Health Minimum Dataset (MHMDS) in April 2013. New linked datasets in the pipeline
- Research uses of data enabled via the Clinical Practice Research Datalink - HSCIC provides data linkage service for CPRD



In Summary

- Transparency and data protection are both important. The challenge is to ensure they jointly co-exist.
- Patients have views and we must respect them
- The HSCIC has a key role to play in the safe release of data to support transparency and innovation

