

Supporting Transparency and Data Protection – What Does This Mean?

NCIN Cancer Outcomes Conference 2013

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What we'll cover...

1. Explore the concept of transparency
 2. Explore what we mean by data protection
 3. Provide an overview of the role of the Health and Social Care Information Centre (HSCIC)
 4. Give some examples of how the HSCIC supports transparency whilst protecting Patient Confidential Data (PCD)
 5. Explore the challenges that brings
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What is transparency?

News > Datablog
DATABLOG
 Facts are sacred
 UK government open data: good bad or dangerous? Tell us what you think
 Cabinet Secretary Francis Maude is launching a major
 Monday 07 November 2011
 The Telegraph

HERE WE KNOW
 State info revolution
 Checks open to all
 THE SUN
 Thursday, 7 July 2011

HM Government
 POLICE.UK
 Overview Crime maps Meet the team Get involved Information and advice
 Data

data.gov.uk^{BETA}
 Opening up government
Cameron's prescription for economic recovery
 Drugs to be fast-tracked in boost for medical research

Open Government Partnership

Source: Cabinet Office 2012

What is transparency?

'Transparency implies openness, communication and accountability'

Source: Wikipedia 2013

'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
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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



What is the HSCIC?



- Launched on 1st April 2013 as an entirely new organisation and as an Executive Non Departmental Public Body
 - 2,000 experts in major ICT programme management, technology, standards, IG, data collection, indicator development ,statistics and analytics
 - Incorporates the majority of functions previously carried out by the former Health & Social Care Information Centre, NHS Connecting for Health & some informatics functions of Strategic Health Authorities
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Our principles

- Build new, constructive and productive relationships with our users, customers, funders and partners
 - Be collaborative, forward-looking, responsive and agile
 - Respond quickly to demand and changing priorities
 - Challenge the way things have been done in the past to ensure continual improvement
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The HSCIC:

- Is the focal point for collection, linkage, secure storage & publication of the core data resources for health and social care
- Brings together into a single place all indicators, the data and details of their methodologies
- Maintains the critical national infrastructure and services that support care delivery
- Approves and accredits local and national IT systems



The HSCIC must also:

- Ensure the proper management of our information assets, protecting personal confidential data as required
- Help people understand the robustness of the information they are using



Identifying the balance between...

- Protecting patient privacy and using data to improve care and outcomes
 - Administrative burden and the increased need to make more national information available
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Some examples

- 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
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The Challenge

HSCIC must:

- Safely release data, allowing and encouraging innovation in support of transparency
 - Be transparent about the data we hold and how we control access to it
 - Earn the trust of patients and the public through our actions
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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
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Questions?
