

Risk and Reward

Why Big Data needn't be
a big problem for privacy

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These are exciting times

It's a shared journey

Electronic Healthcare Records...

Public Health / Disease Surveillance

Disease Registries

Cohort Studies - "Snapshots" or Longitudinal

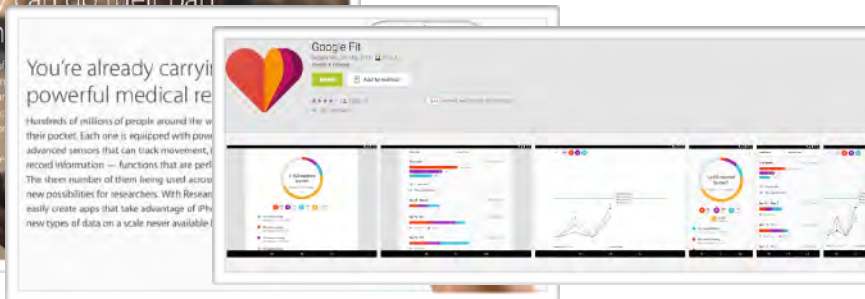
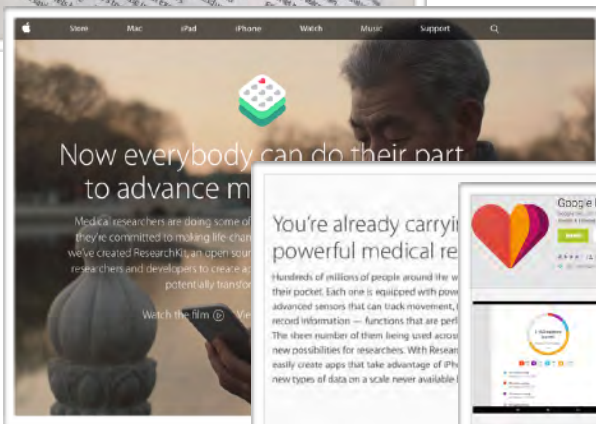
Genomics

Telehealth

Health is holistic, it abhors silos

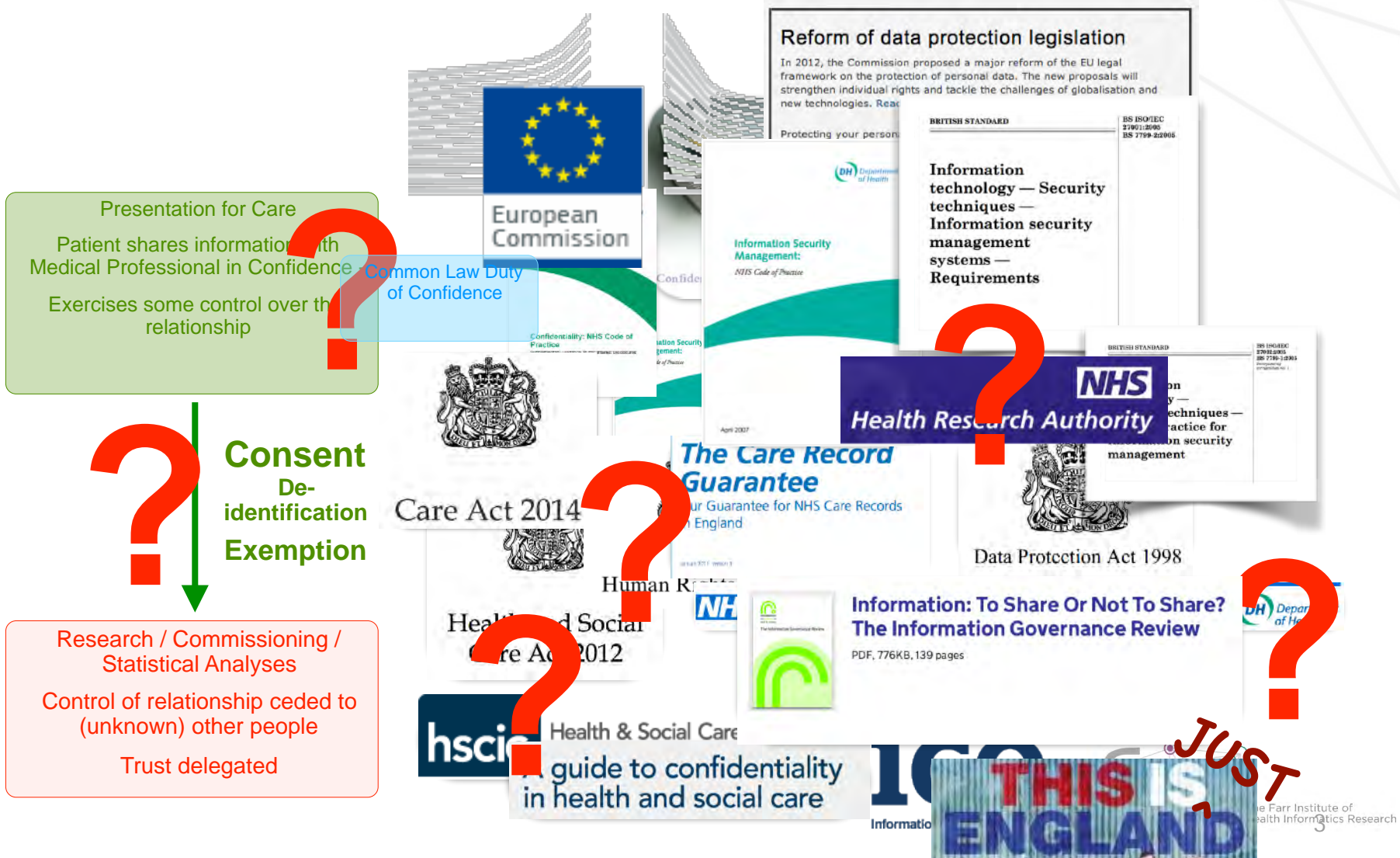
Data

People are partners in their healthcare too - data capture



Health data is governed...

UK Case in point



Health data is governed...

UK Case in point

National Data Guardian for
Health and Care
**Review of Data Security,
Consent and Opt-Outs**

National
Data
Guardian



Safe data, safe care

Report into how data is
safely and securely
managed in the NHS

JULY 2016

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Is it working...?

NHS Trust fined £325,000 following data breach affecting thousands of patients and staff

News release: 1 June 2012

London NHS Trust fined £90,000 for serious data breach

News release: 21 May 2012

GP surgery manager prosecuted for illegally accessing patients' medical records

The screenshot shows the BBC News website interface. At the top, there is a navigation bar with the BBC logo, a 'Sign in' button, and links for News, Sport, Weather, iPlayer, TV, Radio, and CE. Below this is a red banner with the word 'NEWS' in white. Underneath the banner is a secondary navigation bar with links for Home, UK, World, Business, Politics, Tech, Science, Health, Education, and Entertainment. A third navigation bar shows 'England', 'Regions', and 'London' (which is underlined). The main headline reads 'London clinic leaks HIV status of patients' with a sub-headline '2 September 2015 | London'.

ico.
Information Commissioner's Office

farr
The Farr Institute of
Health Informatics Research

Realpolitik

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Health

Care.data: How did it go so wrong?

Nick Triggle
Health correspondent

19 February 2014 Health

Latest Tweets

From Nick Triggle @bricktriggle

Is another fight with health staff brewing? <https://t.co/qb1Tgn1bVL>
8 Days Ago

Strike is off but end to dispute likely to be some way off... <https://t.co/Cs4EGFy1KA>
Last Week

Doctors' strike 'may be called off' <https://t.co/Cs4EGFy1KA>
Last Week

Content from Twitter. Learn more.

Top Stories

Power restored to most storm-hit homes
Most of the homes left without power after severe flooding hit parts of the UK over the weekend, have been reconnected, energy firms say.
18 minutes ago

Republican slam Trump's 'Muslim ban'
2 hours ago

Pistorius bailed over murder conviction
3 hours ago

More from Nick

Savile: Why the risks are real in today's NHS

Greater Manchester: The start of something big?

NHS privatisation: Why the fuse?

There comes a point when the weight of criticism becomes so much that the dam bursts.

For NHS England - and its Care.data project - that point was reached on Tuesday.

When you have a group of bodies as disparate as the British Medical Association, privacy campaign group Big Brother Watch and the Association of Medical Research Charities united in their

theguardian

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Care.data is in chaos. It breaks my heart

Ben Goldacre

Medical data has huge power to do good, but it presents risks too. When leaked, it cannot be unlearned. When lost, public trust cannot be easily regained

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ANALYTICS **ATTACKS / BREACHES** **APP SEC** **CAREERS & PEOPLE** **CLOUD** **ENDPOINT** **IOT** **MOBILE** **OPERATIONS**

ANALYTICS

Healthcare Biggest Offender In 10 Years Of Data Breaches

Missing devices and untrustworthy insiders made the healthcare industry responsible for more (reported) data breaches than any other sector all decade.

Sara Peters
Healthcare

Over the past 10 years of data breach history, 41 percent of breaches were

HOME HOW TO OPT OUT FOR PATIENTS FOR GPs NEWS EVENTS MORE INFO ABOUT CONTACT

medConfidential

KEEP MY SECRETS

How to opt out

A new cock-up has been uncovered, which potentially affects the whole country: care.data itself is currently limited to just four 'pathfinder' areas - and no data has been extracted yet. If you would like to opt out, forms to do so are [here](#). We are working to ensure that NHS England honours all opt-outs and that its promise that this will not affect your direct care is true.

TELL YOUR FRIENDS:

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RIP care.data...

Making sense of all this - the Six Honest Service Men (with thanks to Rudyard Kipling)

Who, what, where, when, why, how

- the why:
 - Confidentiality (medical profession's duty)
 - Privacy (individual's rights must be upheld and respected)
 - Need for information to flow (to share is to care)
 - but securely and ethically
- the what:
 - Data (and therefore Service and Stakeholder) Protection
- Information Security - practicalities: the who, when, where and how

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Risk - how do we handle it?

Identification of information assets records, databases, servers, disks, paper, people etc.



Vulnerabilities - weaknesses of the assets exposed when used (portability, accessibility, value...)

Threats - can exploit a vulnerability to attack an asset

Risk assessment - the likelihood that a threat exploits a vulnerability measured against the potential impact... Defines a mitigation strategy to protect resources



**Theft of hardware/
storage media**



**Worms/
viruses**



**External attackers
(hacker, privacy
advocate, media)**



**Credentials
from privileged
users**



**Accidental
disclosure**



**Reputation and
trust loss**

General Data Protection Regulation

- UK plans to implement it...
- What I like about it
 - individuals empowered with a sense of ownership?
 - local jurisdiction delegations
- **NOT the panacea**
 - *recognises that each member state has its own challenges and traditions wrt confidentiality etc.*
- Requirement for a Data Protection Impact Assessment

UK Farr Innovative Governance Group - what we have learned

- No Magic Bullet[1] and legal compliance is not enough - social licence for research[2]
- From Data Safe Havens to Trusted Research Platforms - a common view has emerged[3]
- Inform and share the governance challenge to foster trust - it is in participants' and civic interest[3]
- Harms of data non-use[4]

[1] Laurie G, Ainsworth J, Cunningham J, et al. On moving targets and magic bullets: Can the UK lead the way with responsible data linkage for health research? *Int J Med Inform* 2015; 84(11):933-40.

[2] Carter P, Laurie GT, Dixon-Woods M. The social licence for research: why care.data ran into trouble. *J Med Ethics* 2015 May;41(5):404-409 and Magic Bullets

[3] Lea NC, Nicholls J, Dobbs C, Sethi N, Cunningham J, Ainsworth J, Heaven M, Peacock T, Peacock A, Jones K, Laurie G, Kalra D, Data Safe Havens and Trust: Toward a Common Understanding of Trusted Research Platforms for Governing Secure and Ethical Health Research, *JMIR Med Inform* 2016;4(2):e22, DOI: 10.2196/medinform.5571, PMID: 27329087, PMCID: 4933798

[4] Jones KH, Laurie G, Stevens L, et al. The other side of the coin: Harm due to the non-use of health-related data. *International Journal of Medical Informatics*; 97:43-51. doi:10.1016/j.ijmedinf.2016.09.010.

What we have learned - EMIF Common Codes of Practice



- Interoperate...
- No “thou shalt”
- More
 - “it is expected that”
 - “it is your responsibility to”
 - “we contract to”



Wider Context - Understanding Relationships and Trust

Neither patient or practitioner may have envisaged wider uses when information first shared in confidence
and neither necessarily know that it is being used elsewhere, de-identified or otherwise

Expectations unknown / misunderstood
left in an unenviable position?
Engagement?

"we don't quite understand what you are doing, so we don't know what to be worried about"

No such thing as total anonymity;
not that useful for reuse?
Duty of confidence set aside by statute / regulatory bodies

Lea, N. C., & Nicholls, J. (2016). Are patient relationships the driver for information governance?. *British Journal of General Practice*. doi:10.3399/bjgp16X685753

How do we
mitigate risk, reap
rewards and
protect privacy?

**“...Don't forget there is a
person at the centre of this...”**
-Dele Olajide

**Confidentiality overarches
data protection
- relationship protection**

**Trust is part of a relationship
you cultivate and support by
demonstrating trustworthiness,
but only individual citizens can
give or take away that trust**

**How? Understand
Human Relationships
and expectations...**

(Farr Response to the National Data Guardian Review)
[http://www.farrinstitute.org/wp-content/uploads/2016/10/
The-Farr-Institute-response-to-NDG-Review-Sept-2016.pdf](http://www.farrinstitute.org/wp-content/uploads/2016/10/The-Farr-Institute-response-to-NDG-Review-Sept-2016.pdf)



On the path to innovation gezelligheid / hygge / gesellig / a user
accueillante / business as unusual...

<https://www.youtube.com/watch?v=y38pgPY6Zq0>



Thank You!

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