Information Revolution: “Choice of Control” to “Choice and Control”

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What does ‘informational privacy’ in the NHS mean?
Are the aims of the Information Revolution (choice and control) a challenge or a solution to the ‘privacy myth’?
What is the role of the NHS verses the role of the individual?
What role can technology play?
The real Information Revolution allowing individuals the choice to conceptualise privacy as...

"Choice of Control" to "Choice and Control"

- CURRENT Proxy-individualistic
- OPTIMAL Control - sociological
- Individualistic
- Boundaries
- Restricted access
- Disclosure - autonomous choice
- Secrecy - dependence and vulnerability

Challenge

Individual privacy v Collective transparency

Choice and control pledged by White Paper: Equality and Excellence: Liberating the NHS

- Law protects individuals’ privacy rights
- NHS masks individual’s roles as “information guardians” for the sake of collective transparency
- ....But there’s no view of collective transparency
The “Privacy Myth” and “Consent”

Confidentiality
- Pre-Information Revolution - The NHS do not have consent from patients, therefore there is no confidentiality.
- Post-Information Revolution - With consent, some individuals will use their power to entrust the NHS with their data entirely, so they owe a duty of confidentiality.

Privacy
- Pre-Information Revolution - The NHS created and continue to propel the privacy myth by creating the element of secrecy.
- Post-Information Revolution - Transparency, power and control or consent (therefore confidentiality) will replace ‘privacy’ as a concept.

Control
- Pre-Information Revolution - The NHS have appointed themselves as having the power to control health records via their exclusive ‘collective transparency’.
- Post-Information Revolution - An alternative to consent is presented as informed choice. Power is offered to the individual to choose whether to control their health records.

Current State of Informational Privacy in NHS

- Proxy-individual stage fuelling the ‘privacy’ myth
- Boundaries already enacted but not transparently - e.g. s.251 NHS Act 2006
- Article 10 ECHR - individual autonomy-based rights
- Primary and secondary control required
- Autonomous right to informational self-determination overtaken by NHS’s positive duties for protecting vulnerabilities
Theoretical and actual roles of Individuals

Individual Privacy

- Use of technical IG controls circumvented by poor requirements management, low uptake and low awareness
- Efforts at ‘viewing’ rights of individuals thwarted by complexity and low awareness e.g. HealthSpace
- Autonomy-based rights circumvented as the individuals’ role is masked
- Reactive redress for individuals at expense of societal good
- Finland, Ashworth, Ackroyd - technical controls per se acceptable
- Information needed to change mindset

Theoretical and Actual roles of the NHS

Individual Privacy & Collective Transparency

- Theoretical role - Technology creates secure infrastructure & process - e.g. IGSoC - framework in place
- In Reality - business processes & mindsets cannot be controlled by the central NHS
- Information utilisation - collective transparency is supported by provisions such as s.251 but it is not transparent
Reflective “MiiFit” and “WiiFit” Model
Mirroring the Roles of the NHS and Individuals

Mindset (Individual)

- Information owners
- Innovation users
- Innovation owners
- Information users
- Welfare mindset

Now : Mindset ruling Information

- Mindset - Privacy myth due to lack of information
  - Individual
    - Individual privacy as an alter-ego of control
    - Privacy options masked by NHS’s self-imposed information guardian proxy-individual role - transparency required
  - Welfare of society
    - Awareness & education - banking industry v. Summary Care Record campaigns
    - Consent
    - Implied/imputed consent
    - Statutory exceptions grown organically to address the void
Vehicle for Transition: Innovation to “disperse power”

- Innovation
  - Facebook style “MiiFit” and “WiiFit” portals
- Individual
  - Interprets DPA for individuals - impartial vehicle
  - Innovation user
- Welfare of society
  - Innovation owner & customer
  - Transparency of positive freedoms to enable autonomy with minimised vulnerabilities

Future: Information ruling Mindset

- Complementary Individual privacy and collective transparency
- Individual
  - Individuals as information owners
    - Individualised - “MiiFit” - HealthSpace
    - Restricted Access - “MiiFit” & “WiiFit” view
    - Boundaries - Access control & Access monitoring IG controls via “MiiFit” & “WiiFit”
    - Control - Sociological control/confidentiality via consent (proxy-sociological) - democracy
- Collective transparency
  - NHS as Information Users
    - Less Information Governance,
    - More Transparent Intelligence Creation
    - More Information Standards
Conclusions

- "Informational privacy" currently has no meaning in the NHS
- Sociological aspects of privacy are considered by the NHS: the framework is fit-for-purpose but the governance structure and accountability and responsibility model is not
- The aims of the Information Revolution (choice and control) offer a solution to the ‘privacy myth’ through the choice of control
- The NHS as “Information Guardian” masks the role of the individual as information owner through the NHS’s self-imposed “proxy-individual” role - the NHS must change mindsets by offering the choice of control
- We offer a solution to the “Privacy myth” - making individual privacy and collective transparency complementary through transparent use of information, with control over the information facilitated through technology via the “MiiFit” and “WiiFit” portals