What researchers should know about confidentiality & privacy

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(non-practising)
Biological samples ≈ Information
Biological images
≈ Information
private & confidential

It has always been accepted that information about a person’s health and treatment for ill-health is both **private** and **confidential**. This stems not only from the confidentiality of the doctor-patient relationship but from the **nature of the information itself**.

Baroness Hale in *Campbell v MGN Ltd* [2004] UKHL 22
confidentiality & privacy law

Creation of obligations towards individuals, in order to protect those individuals (from what?)
Some exceptions ...
Identifiability
Anonymisation
Anonymisation
identifiability & anonymisation

[We] demonstrate experimentally the identification of the presence of genomic DNA of specific individuals within a series of highly complex genomic mixtures, including mixtures where an individual contributes less than 0.1% of the total genomic DNA.

identifiability & anonymisation

Computer scientists have recently undermined our faith in the privacy-protecting power of anonymization ... These scientists have demonstrated they can often ‘reidentify’ or ‘deanonymize’ individuals hidden in anonymized data with astonishing ease ...
identifiability & anonymisation

... we have made a mistake, labored beneath a fundamental misunderstanding, which has assured us much less privacy than we have assumed. This mistake pervades nearly every information privacy law, regulation, and debate, yet regulators and legal scholars have paid it scant attention.

...the guarantee of absolute privacy and confidentiality is not a promise that medical and scientific researchers can deliver any longer.

Joe Bloggs

*research participant*

Privacy?

Confidentiality?
is *all* information identifiable?

To what extent should obligations of *privacy* and *confidentiality* affect the use of (potentially) identifiable information in scientific research?
obligations and implications

If a researcher discovers something about a (identifiable) participant, should they tell them that:

(a) they know something?
(b) what that thing is?
obligations and implications

To what extent should a participant have any say in (a) and (b)?
Are (a) and (b) realistic?
law

Duties (& breaches) of confidence

Data Protection / Human Rights
confidence

Information

necessary quality of confidence

Relationship

obligation of confidence

Restrictions

unauthorised use of the information
confidence

**Some exceptions**
Consent for permitted uses
No consent

*s251 NHS Act 2006 NIGB access to confidential NHS patient info for research*
privacy

Human Rights
right to a private life (article 8 ECHR)
Data Protection
informational privacy & personal data

autonomy?
### article 8 ECHR

**Everyone has the right to respect for his private and family life, his home and his correspondence**

| There shall be no interference by a public authority ... except ... in accordance with the law ... necessary in a democratic society ... national security, public safety ... economic well-being ... prevention of disorder or crime ... protection of health or morals ... protection of the rights and freedoms of others |
privacy & data protection

...the protection of **personal data**, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 ... The domestic law must therefore afford **appropriate safeguards** to prevent any such **communication or disclosure** of personal health data as may be inconsistent with the guarantees in Article 8.

Z v Finland App 22009/93 [1997] ECHR 10
data protection

Protection of fundamental rights and freedoms (privacy) whilst ensuring the free movement of personal data throughout Europe
personal data

data which relate to a living individual who can be identified (a) from those data, or (b) from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller ... includes any expression of opinion ... any indication of the intentions of the data controller or any other person in respect of the individual

Data Protection Act 1998, s 1(1)
data protection:
data controllers

Principles-based system:
Be fair, be lawful, be transparent
Use what you need and no more
Be accurate, be secure, be sensible
Respect individuals’ rights
data protection
& informational privacy

Transparency

Choice?
data protection: data subjects

Info about use of personal data
Resolution of inaccuracies
Object to ‘harmful’ processing

Control over ‘their’ personal data?
data protection: research

Exemptions for researchers:

- Can retain data indefinitely
- Use for secondary purposes
- No right of access
data protection: research

Obligations persist on researchers:

fair & lawful use of data
sufficient information about use of personal data given to research participants