

What researchers should know about confidentiality & privacy

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(non-practising)

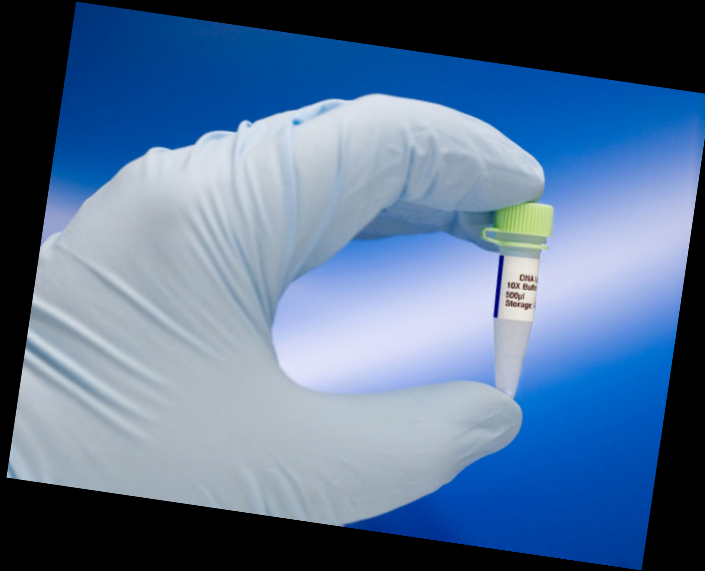
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Biological samples ≈ Information

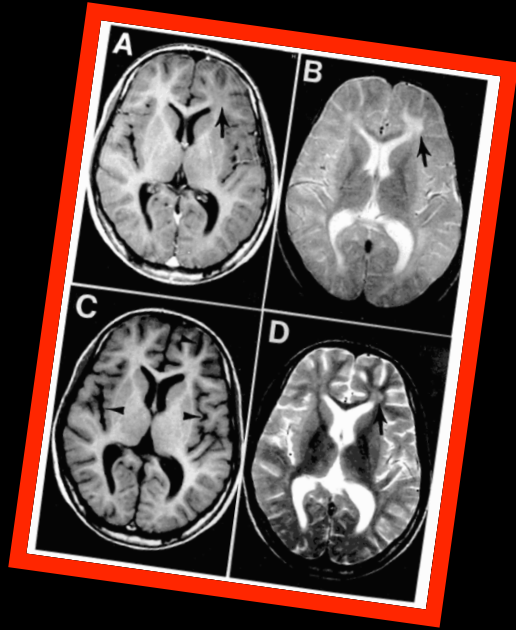
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Biological images \approx Information

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

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Anonymisation

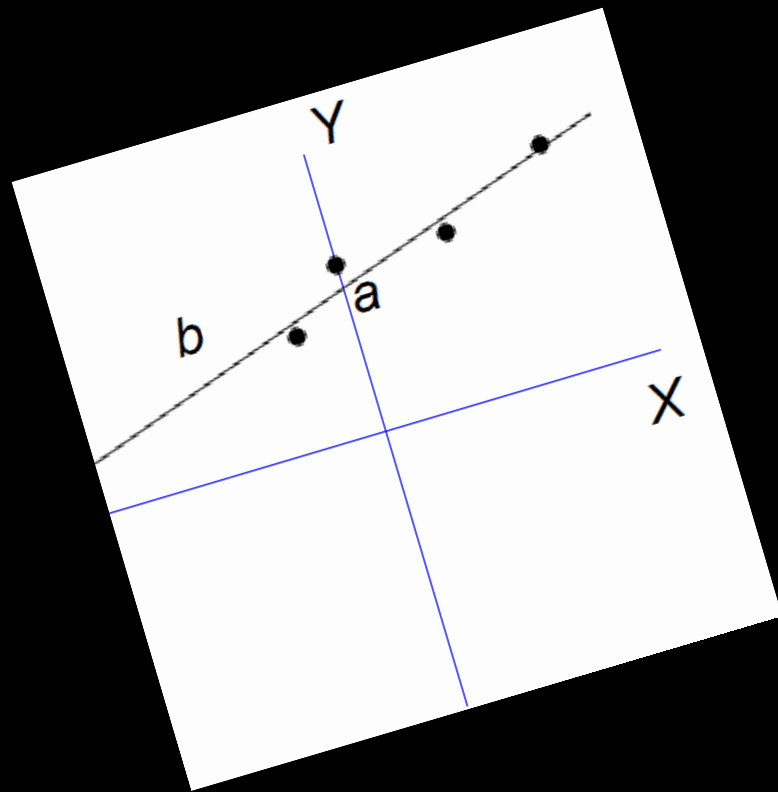
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Anonymisation

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.*

Homer et al. Resolving Individuals Contributing Trace Amounts of DNA to Highly Complex Mixtures Using High-Density SNP Genotyping Microarrays. *PLoS Genet* 4(8) 2008

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 ...

Paul Ohm Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization (August 13, 2009).
University of Colorado Law Legal Studies Research Paper No. 09-12.

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.*

Paul Ohm *Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization* (August 13, 2009).

University of Colorado Law Legal Studies Research Paper No. 09-12.

biological/medical data

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

Lunshof *et al.* From genetic privacy to open consent. *Nat Rev Genet.* 2008 May;9(5):406-11.

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