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The legalities of cancer data release & current risks to obtaining rewards

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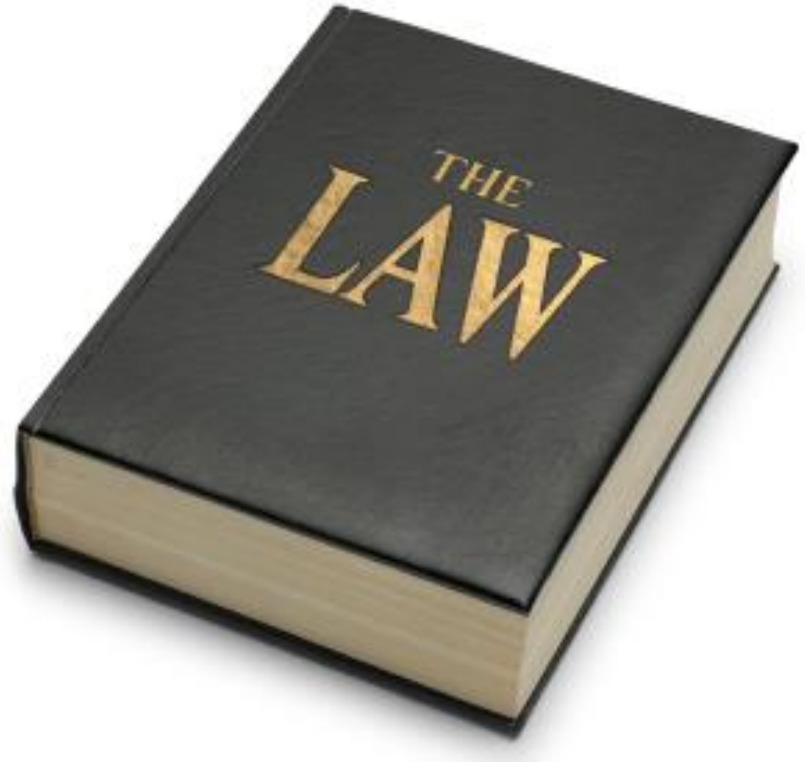
Key topics

1. Legal framework for the disclosure of confidential data
2. Understanding consent



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Legal framework

Use of personal confidential data is governed by common law, Acts of Parliament and statutory instruments:

- The Common Law duty of Confidentiality (Confidentiality)
- The Data Protection Act 1998 (Fair processing)
- The Human Rights Act 1998 (Privacy)

Additional restrictions on specific types of sensitive personal data, e.g. sexually transmitted diseases.

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Common law duty of confidentiality

Protects individuals' private interests and their confidential information.

Four circumstances where disclosure of confidential information is lawful:

- where the patient has given consent
- where there is a statutory basis which permits disclosure
- where disclosure is in the overriding public interest
- where there is a legal duty to disclose e.g. court order

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Consent

Properly gained consent provides a legal basis for sharing confidential information

- Disclosure of essential information
- Comprehension of the risks, benefits and alternatives
- Competency
- Voluntary
- Consent may either explicit or, in certain circumstances, implied.

Patients can change their consent at any time.

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Sharing confidential cancer data without consent

- De-identified release - ‘privacy by design’
- The Health Service (Control of Patient Information) Regulations 2002
  - Regulation 2 (cancer registration)
  - Regulation 5 (S251 support)

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Regulation 2 of the Health Service (Control of Patient Information)

Processing data on patients referred for the diagnosis or treatment of cancer for medical purposes:

- surveillance
- monitoring and audit
- health service planning
- medical research approved by research ethics committees
- the provision of information about individuals who have suffered from a particular disease or condition

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Regulation 5 of the Health Service (Control of Patient Information)

Commonly known as ‘section 251’ - allows the common law duty of confidentiality to be set aside for specific medical purposes when it is

- in the interests of patients or the wider public to do so; and
- impractical to obtain consent; and
- not possible to use anonymised or pseudonymised data.

In certain circumstances, approval under Regulation 5 may be granted to cover essential NHS activity and important medical research.

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Data Protection Act 1998

The DPA provides a framework that governs the processing of information that identifies living individuals:

- Processed fairly and lawfully
- Processed for specified purposes
- Adequate, relevant and not excessive
- Accurate and kept up to date
- Not kept for longer than necessary
- Processed in accordance with the rights of data subjects
- Protected by appropriate security (practical and organisational)
- Not transferred outside the EEA without adequate protection

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Summary….

All processing of confidential information must be lawful.

In addition to having one of these legal bases the processing must also meet the requirements of the Data Protection Act.

Any processing of confidential information that is not compliant with these laws, even if otherwise compliant with the Data Protection Act, is a data breach, and must be dealt with as such.

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What does the Office for Data Release actually do?

The ODR is committed to striking a balance between safeguarding an individual's privacy and making best possible use of the data available:

- Signpost to expertise within PHE teams
- Scruntise requests to access Data held by PHE
- Ensure contractual controls are placed on prospective data recipients (where data is required for non–direct care)

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Managing risk with reward

Risk management involves three key elements

1) Systematically assess confidentiality risks
   - spontaneous recognition (i.e rare disease/unusual job etc)
   - Malicious/deliberate attempts to re-identify
2) Avoid or mitigate identified risks
   - Anonymisation code of practice
3) Managing the remaining risks
   - Data sharing contracts

Caldicott: *'Information: To share or not to share?'* need for balance between the protection of patient information and the use and sharing of information to improve patient care.

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Mitigating risk – what do we do?

- Control processing activities – data sharing contract
- Limited the number of variables – only those justified and critical to project
- Apply anonymisation techniques:
  - Introducing small amounts of random error (e.g. rounding or data swapping);
  - Groupings (e.g. giving age in five year ranges);
  - suppressing particular values or records that cannot otherwise be protected from the risk of identification


Hello, I'm Peter.
We haven't met before but one day you could save my life.
Sharing your patient record can help researchers save and improve lives.
Researchers can use patient records to gain knowledge and experience to treat illness and combat disease. This month the NHS will write to all households in England explaining how patient records will be shared.
For more information about your choices and why this matters visit: patientrecords.org.uk
Supported by
Arthritis Research UK
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The NHS Constitution states

THE NHS CONSTITUTION
the NHS belongs to us all

"You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered".

Type 1 objection: Patients can object to information about them leaving a general practice in identifiable form for purposes other than direct care, so confidential information about them will not be shared.

Type 2 objection: Patients can object to information about them leaving the HSCIC in identifiable form, so confidential information about them will not be made available by the HSCIC other than for purposes of direct care.