Legitimate relationships?

When do you need consent?

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Discussion

* GP data – when is implied consent enough?
* When is specific consent required?
* Who should have access
* What should they have access to?
* Is access prior to an appointment OK ?
* What to do for specific consent in the above

Types of information

* Personal Identifiable information
* Pseudonymised information
* Anonymised information
* Anonymous information

Uses of the information for..

* Direct personal care
* Secondary uses in HSC
    * Anonymized
    * Pseudonymized
    * Identifiable
* Secondary uses for non health (and Social Care purposes)

Models of consent important

* Improved information sharing
* ECS
* KIS
* ECR
* Increasing interest in secondary uses

The law governing consent

* The Common Law – this holds the key principles
* The Human Rights Act 1998 (UK)
* Data Protection Act 1998 (UK)
* Freedom of Information Act 2000 (UK)
* Criminal Law Act 1967
* Public Health Act 1967
* Health and safety at work
* Mental Health Act

And also…

* Aids (Control) Act
* Human Fertilisation and Embryology Act 1990
* Police and Criminal Evidence Act 1989
* Criminal Appeal Act 1995
* Terrorism Act 2000
* Sexual Offences Act 2003
* Serious Crime Act 2007
* And so on….

Definition of Confidential Personal Information

* A duty of confidence arises when one person discloses information to another (eg patient to clinician, service user or carer to social worker) in circumstances where it is reasonable to expect that the information will be held in confidence

Right to confidentiality

* Patients have a right to keep their information private
* This is not an absolute
* Requires balance of the individuals right vs society
* Information is confidential and should not be disclosed without consent except where..
    * The law requires it
    * Certain circumstances in the public interest eg serious crime

The common law

* Key principle is that service user information is confidential unless consent to disclose has been given.
* Before making disclosure in the public interest eg to the police must satisfy themselves that it is sufficiently in the public interest to warrant waiving their duty to confidentiality.
* If unsure then confidentiality should not be breached and the reason explained. The police may then ask a judge to issue a witness summons on the basis that the public interest requires disclosure.

The Data Protection Act 1998 Principles

1. Personal data shall be processed fairly and lawfully
2. Obtained for one or more specified purposes
3. Adequate, relevant and not excessive
4. Accurate and kept up to date
5. Not held for longer than is necessary
6. Rights of the Data Subject
7. Technical and organisational measure to prevent unauthorised access, use or loss of personal data
8. Not transferred outside the EEA unless the country ensures an adequate level of protection

The purpose of use or disclosure

* The direct care of that service user
* Purposes not directly related to care of that service user
* Purposes not related to the care of the service user.

Direct Patient Care - Consent

* Consent may be inferred from their acceptance of that care

Purposes not directly related to the care of that service user

* Examples of secondary uses include
  * Public health monitoring
  * Registries
  * Infectious disease reporting
  * Planning
  * Financial management
  * Commissioning
  * Risk management
  * Investigating complaints
  * Health and social care research
  * Teaching

Consent for Purposes not directly related to that service user

* The express consent of that service user is usually required unless a legal basis for the disclosure exists or there is an overriding public interest in the use or disclosure

Balancing the two interests

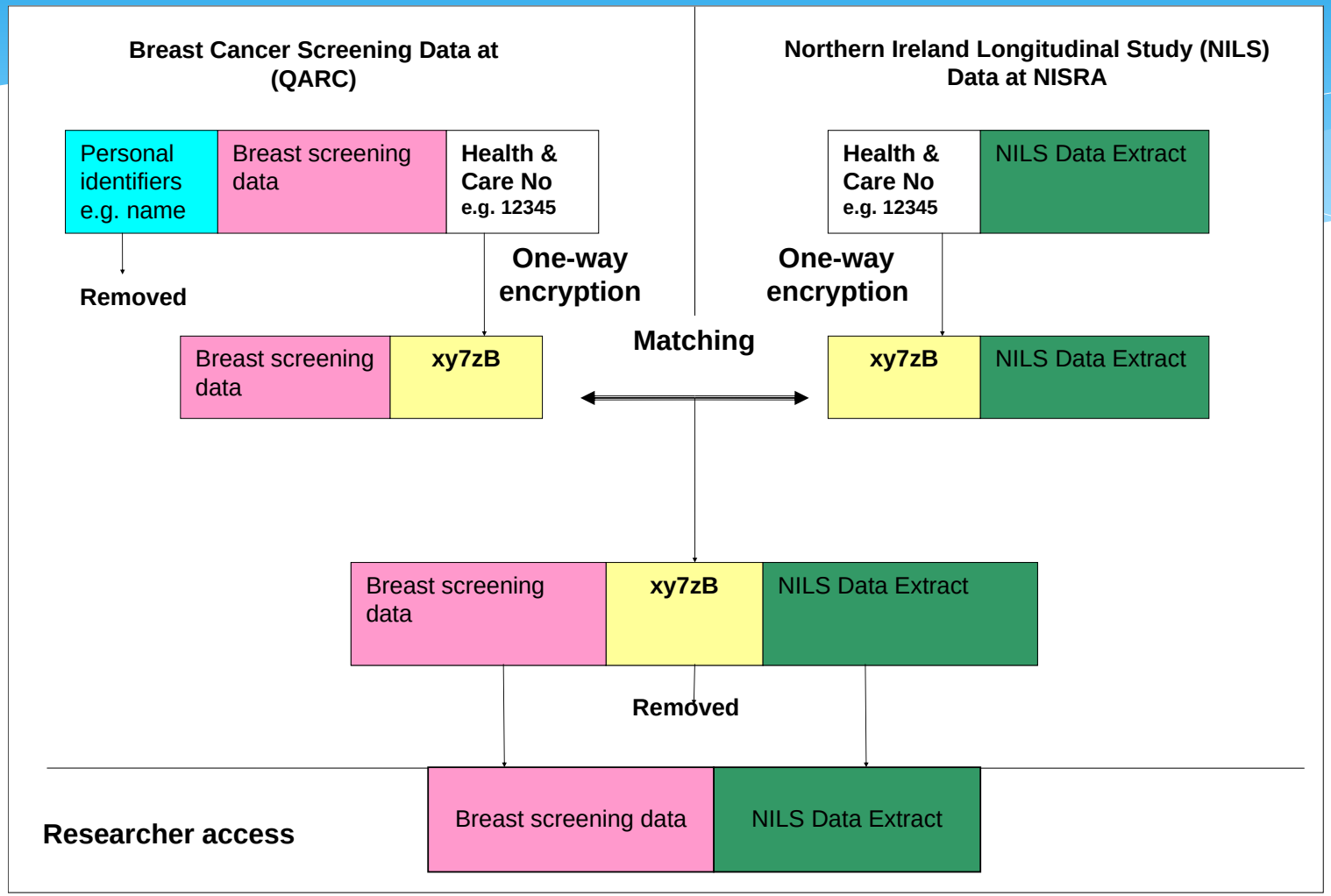
* On occasions there is a need to balance
* 1. the individuals right to maintaining confidentiality or obtaining consent and
* 2. the strong public interest in the running of an efficient and quality service.
* NI does not have provision such as section 251 of the NHS Act which allows the common law duty of confidentiality to be set aside (as advised by the ECC in England)

Consent for purposes not related to the care of the service user

* Consent is required unless…
* Legally obligatory disclosure – statutory reason
* Legally justified disclosure – in the overriding public interest
* Balancing the interests can be difficult
* Test is one of strict necessity
* Each case must be judged on its merits

Secondary Uses

* The use of anonymised or pseudonymised information where possible – does not require specific consent
* Increasing desire to “link” information and use of pseudonymised information
* Provides a way to satisfy legitimate need to have information without breaching confidentiality


Breast Cancer Screening Data at (QARC)
Northern Ireland Longitudinal Study (NILS) Data at NISRA
Personal identifiers e.g. name
Breast screening data
Health & Care No e.g. 12345
Health & Care No e.g. 12345
NILS Data Extract
Removed
One-way encryption
One-way encryption
Matching
Breast screening data
xy7zB
xy7zB
NILS Data Extract
Breast screening data
xy7zB
NILS Data Extract
Removed
Researcher access
Breast screening data
NILS Data Extract

Consent models for Direct Care

* Implied consent the norm
* Normally consent is inferred from the patients acceptance of treatment e.g. referral to hospital
* Normally there is an expectation that relevant information to support the delivery of care will be shared
* What about information given in one place but published in another e.g. ECS?

Wider information sharing

* What about GP information shared with Trusts
* What about Trust information shared between with other Trusts
* Scotland or NI wide information
* What models of consent are appropriate
* Implied to send – specific to view
* When do we need specific consent?

Who should the information be shared with

* Doctor to doctor
* Nurse to nurse
* Doctor to nurse
* Clinician to clinician
* Administrative staff
* Non clerical staff
* Important point is a legitimate relationship

Legitimate relationships

* Normally this means a treating or caring relationship with the patient
* If the patients has been referred is it OK to view?
* Who on the team has a legitimate relationship
* Role based access
* What parts of the record should be available and to whom?
* How to maintain public (and professional) confidence

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