



From Privacy to Information Governance

Dr Petra Wilson
Internet Business Solutions Group - Cisco

Historically

- One-to-one relationships based on traditional medical privacy
- Doctor owned and controlled records
- Passive patients

The Changing face of Healthcare delivery in Europe

Patients are no longer registered with individual general practitioners but registered with multi-partner practices or use walk-in centres.

GPs are no longer the sole gatekeepers to healthcare.

Wider range of healthcare delivered by nurses and pharmacists with extended roles.

Increasing numbers of healthcare professionals are seeking to work part-time.

More specialist care delivered in co-operation with GPs

The rise of the resourceful patient (the decline of the sapiential authority of the GP) .

The rise of personal health management and health consumerism.

Significant investments in information management in healthcare.

The Current Conundrum

Doctors have a legal and ethical duty of confidentiality for all identifiable health information learnt in a professional capacity.

AND

Patients expect doctors to share relevant information appropriately, making it promptly accessible when necessary their care.

AND

If the expectation of appropriate sharing is not met patients will withhold information to the detriment of their own and other peoples' care.

From Privacy to Data Protection

Medical Data Processing is prohibited

(Art 8 Directive 95/46/EC)

unless:

Explicit informed consent has been obtained from the data subject (article 8(2)(b)).

Or

It is in **vital interests** of the patient or of another person, AND the data subject is physically or legally incapable of giving consent (article 8(2)(c)).

Or

it is necessary for **preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services** AND the personal data in question are **processed by a health professional** (article 8(3)).

Or

if there is a **substantial public interest** in the processing (article 8(4)).

Explicit and Informed consent

- creation of medical records is a necessary and unavoidable consequence of the medical situation
- Withholding of consent may be to the patient's detriment.
- All possible future users and purposes cannot be known at time of creation

Explicit and Informed consent for EHR

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CONSENT ????

Vital Interests

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Vital Interests ?????

Preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services

- Must be processed by a healthcare professional
- “required” – not merely useful
- doubtful if this is adequate justification for collection of all medical data

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**Required for care and treatment
???????**

Public Interest

if there is a substantial public interest in the processing, special rules may be adopted

..... So what would those rules look like?

From Data Protection to Public Interest Information Governance

Data should be:

- fairly and lawfully collected processed;
- Collected with knowledge and agreement of data subject (implied or explicit)
- processed for known /knowable and limited purposes;
- accurate, adequate, relevant and not excessive;
- not kept for longer than is necessary;
- processed in line with data subjects' rights of access and correction
- securely stored and shared

Public Interest based Medical Information Governance

- ***Consent***

- Implicit consent and opt-out system for general information

- opt-in for sensitive information

- (visible) Sealed envelopes

- Personalised privacy rules

..... Public Information Campaigns

Public Interest based Information Governance

- ***Security and Authenticity***

Strong authentication techniques

electronic signatures

Audit Trail

Appropriate anonymisation (PETs)

..... visible correction ??

Public Interest based Information Governance

- **Access**

- Role dependent authorization (inc. patient)

- Patient defined emergency access

- Audit trail of all access

Public Interest based Information Governance

- ***Ownership and Control***

Patient

Named healthcare professional

National Health System

..... Liability, replaceability, accuracy

**Public Interest based
Information Governance
.....Creating balance
between patient
confidentiality and access
to patient information by
healthcare professionals**

Thank you

