



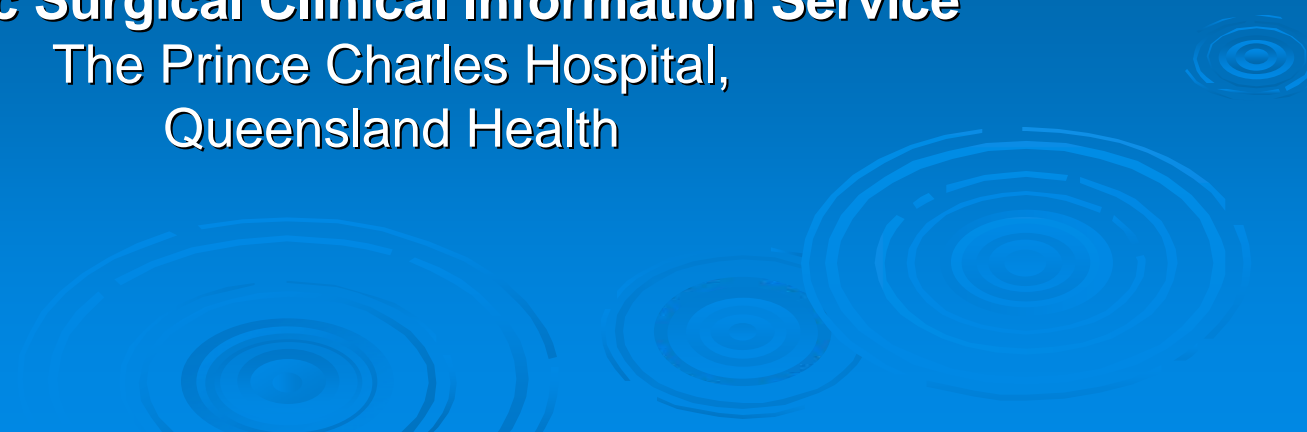
Health Privacy Futures 08

Workshop 2

The Healthcare Professional's Perspective

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Outline

- questions in current Privacy Management
- issues of concern
- underlying ethics and concepts
- positive goals in privacy
- undesirable consequences
- Privacy Management tools at the front line





Questions in Current Privacy Management

- What might go through a Healthcare Professional's mind when negotiating Privacy in a particular clinical setting?
 - Eg doctor/ nurse/ therapist/
 - diagnostics/ health sciences/
 - epidemiologist/ infection control officer/ clinical Informatician
 - other health service practitioner interacting with clinical information as part of health practice



Questions

- **What** are we trying to achieve with Privacy management? **Why** are we doing this?
- What is the purpose of their activity and how does Privacy relate to
 - Protection and assist care of the patient
 - Facilitation of a healthcare service
 - administrative to strategic level
 - Quality Assurance
 - Research



Questions

- **Who** is involved? Who
 - does privacy and privacy regulation relate to?
 - has responsibility?
- **Where** do you get information and knowledge on Health Privacy?
 - What resources are there and which specifically apply?
- **How** do we manage Health Privacy in our particular environment?



Issues of Concern

Healthcare Professional in the hospital setting

The Patient

- Protection and safety
- Their rights/autonomy
- Desensitisation to or depersonalisation of personal information

“BOTPA”

- The *Privacy Act* being used inappropriately as a reason for failing to provide information or assistance
- Over-interpretation of Privacy regulation
- Inappropriate hindrance of health services - safety
- Unnecessary hindrance of Medical Research and Public Health




Issues of Concern

Healthcare Professional in the hospital setting

Transparency and Accountability

- Informing the public
- Lines of accountability
 - Patient
 - Clinician (Clinical Informatician/ Data manager)
 - Health service organisation
- Auditing Privacy Management

Information/Data Management processes

- Data Quality
 - audit trails
 - register/database management
 - staff and training
 - registry governance
- 



Issues of Concern

Healthcare Professional in the hospital setting

Data Use

- Access, Use, Disclosure
- Patient access - FOI
- Authorisation
- Management

Consent issues

- Implied/ explicit/ opt on/ opt off/ waiver ('gifting')
- Context dependent
- When should you ask for consent? When **shouldn't** you ask for consent?



Underlying Ethics and Concepts

- Balance, undesirable consequences and positive goals in privacy for interpretation of local regulation – an example





Cardiac Surgical Register




Response to increased Privacy regulation – journey of discovery particularly over last 5-6 years following QH privacy reviews and implementation of administrative regulations


How to address the Privacy regulations wrt the Cardiac Surgical Register required:

- Defining our purpose and context
- identifying the relevant legislation
- understanding the underlying ethics and concepts,
- identifying relevant resources
- Privacy mapping process against the relevant legislation
- developing localised privacy management tools addressing identified relevant aspects of the applicable privacy regulations




Context

- Cardiac Surgical Register: risk, procedure, outcomes data
 - over 50 000 clinical records over 30 years over 3 software platforms
 - Primarily QA focussed, supports clinical research
 - No specific consent
 - Information is available to:
 - support clinicians in their treatment decisions
 - inform consumers about services (and risks) they receive
 - facilitate Cardiac Surgical program management
 - facilitate Cardiac Surgical program Quality Assurance
 - inform policy makers in planning and paying for services
- 
- 
- 



CSR: Privacy issue for main review: *Data Access, Use and Disclosure*

What data uses are

- allowed
 - patient care
 - primary use
 - aggregate/ de-identified
 - consented
 - special exceptions
 - not allowed uses
 - unrelated purpose
 - no consent
- 



Definitions

Primary vs Secondary purposes

➤ Primary


- directly related to the health service or within reasonable expectation
- ? Funding, Management, Quality Assurance, Quality Improvement

➤ Secondary purposes

- Research
- Many definitions
- Authorisation and regulation of different types of use



Developing Local Guidelines

- How to develop local guidelines wrt data request?
 - Can be difficult to determine exact obligations from institutional general policies and difficult to develop service level policies from the regulations
 - terminology may be confusing and may not be well defined
 - what parts apply
 - Useful to consider the underlying concepts, ethics and societal values
 - Basis of legislation and assists interpretation
- 



Ethical Basis

- Bioethics identifies: beneficence, respect for persons, and justice
- Clinical principle precept: 'First Do No Harm'

However

- Opposing ethics schools of thought defining "how one should act",
 - Eg Kantian: focussed on the actual action and the morality of that action as opposed to the consequence of that action. As long as you act in a moral way then the consequences of your actions don't matter
 - Utilitarianism: the idea that the moral worth of an action is solely determined by its contribution to overall utility, that is, its contribution to good as summed among all persons



Balance and Proportionality

Concepts of Balance and Proportionality

- To balance fairly requires educated weighing of risks and benefits of the alternatives against each other and accepting a certain level of risk in return for desirable benefit


In the context of data use and disclosure this considers

- Individual autonomy/right to non-interference vs public interest in the benefit of the use
- Health service staff responsibilities to patient vs service user (patient) responsibilities to health service provider



Goals

Positive goals for implementing Privacy management:

- Ensure responsible handling of health information wrt privacy
 - Enhance ability of individuals to be informed about their health care
 - Promote provision of quality health services
 - Balance public interest in protecting privacy with public interest in legitimate use of information
- 



Unintended Consequences

- non-application
 - breach of privacy
 - individual embarrassment or possible patient harm
 - loss of public trust in healthcare system
 - over-interpretation/ misinterpretation could lead to:
 - reduced collaboration between carers
 - increased cost of healthcare
 - decreased quality of healthcare
 - hindrance of medical research
- 



Tools

Tools for managing Privacy in data access, use and disclosure for CSR

- SOP of Clinical Pathways –
 - Data Reporting and Access Policy - authorisation and delegations
 - Data Request Form – for decision support and authorisation

Cardiac Surgical Clinical Information Service
CARDIAC SURGICAL REGISTER - CLINICAL INFORMATION REQUEST

NAME: _____ DATE: ___/___/___ Ph: _____

I seek approval to be provided with the following clinical information from the Cardiac Surgical Register provided by the Cardiac Surgical Clinical Information Service.

Title and purpose of request (i.e. what the data will be used for)

Data parameters: (please list)

Data date parameters: From To Data required by:/...../.....

Is the intended recipient of this data a Qld Health Employee? Yes No

If No specify organisation affiliation: _____

Is only patient de-identified /aggregate data required? Yes No

Will this data contribute to "evaluating, managing, monitoring, or planning health services"?
(E.g. Clinical Audit, benchmarking, comparing with other institutions results) Yes No

Will this data contribute to Quality Assurance/Clinical Improvement activity?
(Includes scoping of topic for QA/QI/Research purposes) Yes No

Is it intended that this data will contribute towards a publication?
(Most journals require HREC approval for publications using clinical data from clinical information systems) Yes No

If Yes, has a letter been drafted to HREC Yes No

Is this data required as part of a Research project? Yes No

If Yes, specify HREC Approval reference number: _____

I understand that this data must be used in accordance with Part 7 of the Queensland Health Services Act, 1991, section 62A and the Commonwealth Privacy Act. Identifying confidential information will only be used where it is impractical to use unidentified data. Publications will not include any identifying data. This data will not be used for any purpose other than that specified and will not be disclosed to any other person without additional specific authorisation.

Signed: Date: .../.../.....

Return signed request to CSCIS- Rm. 8, 5th floor, Clin Sciences Bld - Ext 8882 or Secretary Director Card Surg

Authorisation level according to Delegation of Authority protocol:...

Approved by /...../..... Position:.....

For urgent requests only: phone approval given/...../.....

Office use only: Request ID No:
REQUEST.DOC

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Tools

- Data Request database – for Audit and accountability
- Practical definitions and specific examples for local context
 - Primary purpose
 - Secondary Purpose
 - Clinical monitoring - Quality Improvement - Research
 - Reasonableness
 - Identifiable - de-identified - re-identifiable
- Information sessions for possible requestors (eg registrars, clinical placement students)



Summary

- Define your activity purpose and the role or use of information
- Determine the regulations relevant to your situation
- Understand the meaning behind the regulations to facilitate interpretation
- Map your activity against the relevant regulations
- Create locally applicable policy or guidelines to support good privacy management practice including succinct practical definitions
- Educate

And Finally

Privacy Regulation should enhance patient care and health services

- Don't underestimate the importance of Privacy in Healthcare
- But lookout for unintended consequences

