



Ethics and the Protection of Information Privacy

Health Privacy Futures 2008

Realising the Opportunity

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What is privacy?

ALRC report recognizes four domains:

- Information privacy
- Bodily privacy
- Privacy of communications
- Territorial privacy

ALRC accepted intractable difficulty of defining privacy

Discusses the

- status and
- characteristics of privacy



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Status of privacy

STATUS

- ALRC preferred to describe the status of privacy as a bundle of interests, rather than a right
- Recognizing that interests compete – interests in privacy competes with interests in
 - freedom of expression,
 - protection from abuse, and
 - national security



Characteristics of privacy

CHARACTERISTICS

Privacy interconnected web of disruptions of practices,
Disruptions & experience with the Privacy Act provide
the necessary focal points for the ALRC review
Pragmatic rather than theoretical



Ethics and privacy

An ethical analysis seeks theoretical framework in all four domains

- Information privacy
- Bodily privacy
- Privacy of communications
- Territorial privacy

Restricted access conception = that privacy is about restricted access to persons or information about persons (Ruth Gavison, Anita Allen)



Ethics and privacy

James Moor proposes there can be situations that are either

- naturally private, or
- normatively private

Naturally e.g. complete isolation

Normatively – where people ought, morally or legally, to be restricted in access to people or information about them



Ethics and privacy

Situations that are normatively private are

- Culturally determined
- Contestable

In information privacy, contestable issues include:

What information should be protected by restricted access?

What kind of restrictions should be used?

In what situations?

Personal information is a type of information access to which should be restricted.



Ethics and privacy

- Cultural normative privacy equivalent of natural privacy would = personal information could be collected, used or disclosed ONLY with the consent (“the consent rule”) of the person
- Ethical basis for such a rule: respects autonomy of individuals
- Respect in turn allows people to live and order the life that they choose for themselves (NZLC)
- Two important problems with the consent rule:
 1. It ignores other competing interests
 2. The concept of autonomy



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Competing interests

- As ALRC and NZLC recognize, my interest in restricting access to my personal information can compete with other interests
- Existing privacy and other laws already express the relative weight society gives to some of those
- In the ALRC report, examples are interests in
 - Lessening/preventing serious threat to another individual's life, health or safety or to public health or public safety
 - Suspicion/discovery of unlawful behaviour
 - Authorisation/requirement under law
 - Law enforcement



Autonomy - atomistic

- Prevailing conception of autonomy in bioethics in recent decades
- Autonomous individual capable of rational choices that will fulfill personal goals (choosing to live one's life ordered as one desires)
- Assumes & promotes a deeply individualistic, atomistic view of humans
- Encourages language of personal control, ownership – “the privacy paradigm”



Autonomy - relational

- Revised conception advanced (Catriona Mackenzie)
- Recognises that autonomy is learned, maintained and even constituted by the relationships in which individuals grow and live
- Autonomy is relational not atomistic
- Choices about life would, and do, reflect this relational situation
- Such an autonomous person could be expected consent to access to personal information because of the relational value of disclosure



Autonomy - principled

Other philosophers have advanced revised concepts of autonomy

“A person whose desires and impulses are her own and express her nature as it has developed and been modified by her own culture has character. People with character contribute to well-being of human kind so that liberty to develop that character is essential.”

Principled autonomy - that expresses principles that could be adopted by all others

(Onora O’Neill, Gifford lectures, Autonomy and Trust)



Autonomy - Samoan culture

Palagi self

Self that is
individuated
Anatomically bound
Self actualised
Self privileges the
rational elements

Samoan self

Self is relational
Draws uniqueness
from its places of
belonging
from Tupuaga
(genealogically
located)
or Faasinomaga
(belonging) & Tofiga
(responsibilities)

Source: Tafaoimalo Loudeen Parsons

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Aboriginal and Torres Strait Islander culture

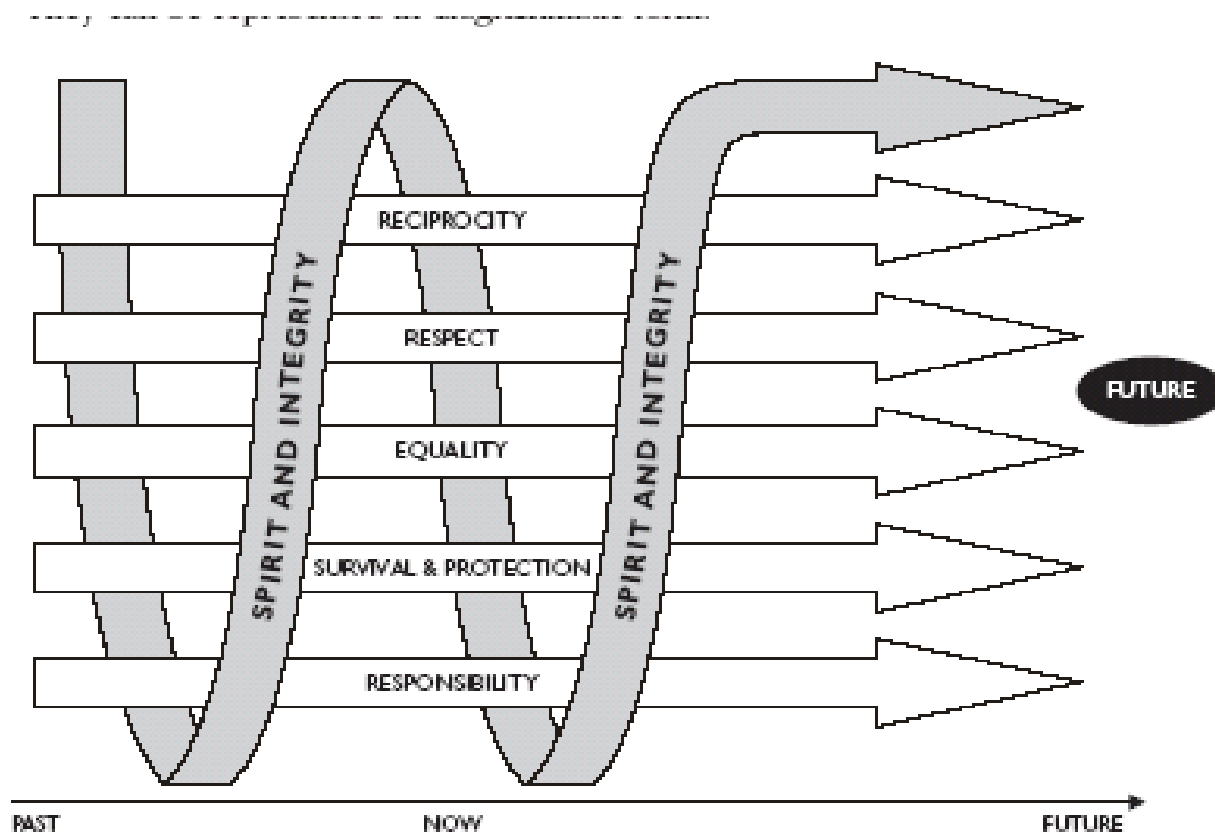


Diagram 1: Aboriginal and Torres Strait Islander Peoples values relevant to health research ethics

Source: Values and Ethics: Guidelines for Ethical Conduct of Aboriginal and Torres Strait Islander Health Research, NHMRC, 2003

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Re-thinking autonomy

If we adopted a new view of autonomy - such as relational or principled autonomy, or drew on indigenous culture, would that promote a more balanced view of:

- the rights and responsibilities of Australians,
- the requirements for consent to use of personal information, and
- the criteria for ethics committee decisions in the absence of consent?



Re-thinking autonomy

Revised *National Statement on the Ethical Conduct in Human Research* has begun this

Authorises consent to participation in research that is:

- Specific - to a research project
- Extended - to similar research
- Unspecified - to any research

These situations offer room for reliance on relational or principled autonomy as the basis for guidance, education and reassurance

That an autonomous decision need not be confined to an individualistic one



Re-thinking autonomy

- Such a revised view will be important in situations in which our society has not definitively established the relative weights of interests that compete with that in personal privacy
- Where “the consent rule” is contested
- One of the key situations is the collection, use or disclosure of health information for research, without consent



Personal information, research & consent

- ALRC proposal is broadly speaking to continue to current arrangements that rely on an independent decision-maker to weigh the interests in privacy and in the proposed research
- Critical issues are:
 - Defining research
 - Justifying not seeking consent
 - Criteria for weighing the interests
 - Qualifications of the decision maker



Defining research

Quality assurance

ALRC proposes that use and disclosure of health information

- for a directly related secondary purpose
- that a person would reasonably expect.

Not significantly different from present situation

OFPC's guidelines clearly include quality assurance processes within this provision



Defining research

ALRC proposes

- to include all research, not only health and medical, in the definition
- to make clear that the compilation or analysis of statistics is within the meaning of research for the purposes of the Act

More stakeholders will need to be involved in development of research rules



Justifying not seeking consent

ALRC proposes that it must be impracticable or unreasonable to seek consent to the use of personal information for research before it can be used for research in the absence of consent

Research Rules mainly directed to agencies and organizations, rather than HRECs



Criteria for the weighing of interests

ALRC proposes

- that an HREC must be satisfied that public interest in the research outweighs the public interest in maintaining the level of privacy protection provided by the Privacy Act
- to remove the current “substantially outweighs” test
- that National Statement offer guidance to HRECs
- to reduce risk of “conservative” decisions by HRECs, e.g. those presuming an individualistic autonomy



NS criteria for HREC waiver of consent

National Statement requires HRECs to decide about waiving consent, where

- Research is low risk
- Benefits justify risks of harm with not seeking consent
- Impracticable to obtain consent
- No reason to think participants would not have consented
- Sufficient protection of privacy
- Adequate plan to protect confidentiality of data
- Where practicable, plan for welfare information available
- Commercial possibilities not deprive of entitled benefits
- Waiver not prohibited by law

May need revision



Qualifications of decision-maker

ALRC proposes retaining reliance on HRECs

National Statement requires institutions that establish HRECs to:

- resource them adequately (NS 5.1.26)
- set terms of reference (NS 5.1.27)
- ensure members have relevant expertise, induction, continuing education (NS 5.1.28(b))
- ensure HREC has access to “expertise necessary to enable it to address the ethical issues arising from the categories of research that it is likely to consider.” (NS 5.1.33)

Issuers of NS – NHMRC, ARC and UA – will need to be involved in Research Rules and NS amendments



Qualifications of decision-makers

What do we expect of HRECs?

Required composition of 8:

- Chair,
- Layman and laywoman
- Professional care, counselling
- Pastoral community role
- Lawyer
- Current and relevant research experience

What image represents the role and function of HRECs?



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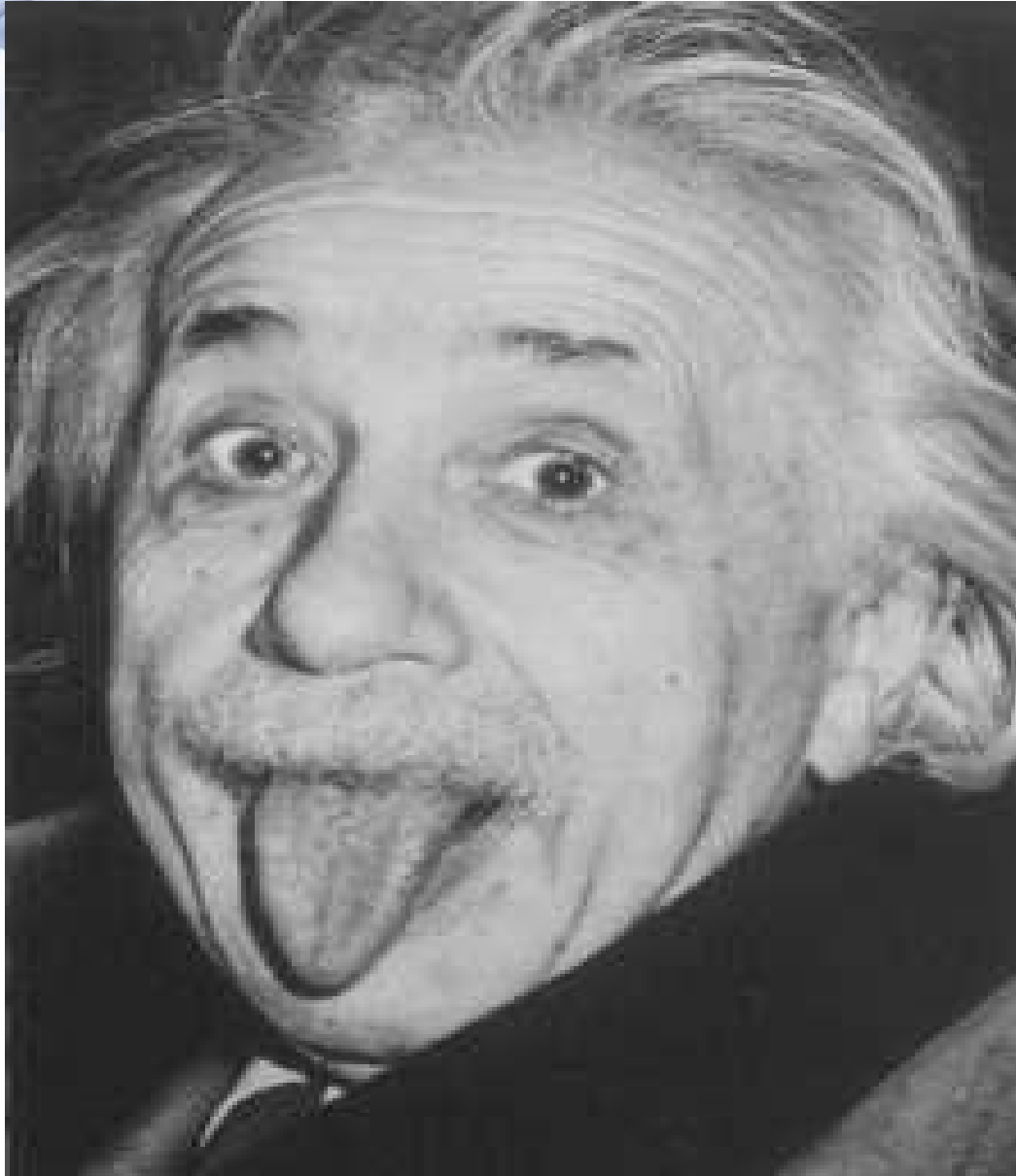


HRECs as moralists?

- Authority from asserted superior moral or ethical insight
- Decide for others
- Justification by authority alone: we are the ethics committee and we know what is acceptable and what is not



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HRECs as philosophers

- Authority from learning & status
- Offer explanation and justification for all alternative decisions
- Clarify the choices and justifications available



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HRECs as lawyers

- Authority from professional status
- Decide by applying rules and laws to situations
- Justification by interpretation



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HRECs as coaches

- Authority from experience
- Provide strategies for others to use in deciding
- Justify advice by principles, values and experience
- Operate within boundaries set by laws



Ethics and decisions

- Strategies for ethical decision making have justifications on several levels:
 - acts or decisions often justified by rules
 - rules often justified by principles
 - principles justified by theories or values
- Example: consent or refusal to allow use of personal information in research



Decision/Act: consent or refusal



Rule: that individuals decide for themselves



Principle: autonomous decisions of individuals
are respected



Theories or values:
choice expresses intrinsic human value
OR
Choice maximises beneficial outcomes



HRECs as coach

- Need continuing education about guidelines, principles and values
- So that decisions are seen to be based on guidelines
- Knowing the principles that justify the guidelines
- Recognising the range of relevant values that society draws on.



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Ethics, information and human research

- Is there a wider ethical and educational task that needs to be undertaken?
- To rethink & rebuild a shared ethical understanding about personal information and social knowledge in human research
- From one based largely on an autonomy of atomistic independence
- To one that reflects a contemporary understanding of relational or principled autonomy and community