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The right not to know:
Is it meaningful for law, policy and practice?

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The rhetoric of the right not to know

- The Right Not to Know is a contested matter (RNTK)
- Illogical and inconsistent with self-authorship
- A right NOT to know is as inappropriate appeal to rights
- Successful claims place impossible responsibilities on others

RNTK in international legal instruments

- *UNESCO Universal Declaration on the Human Genome and Human Rights (1997), Article 5c provides:*

  "The right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected."

- *Council of Europe Oviedo Convention on Human Rights and Biomedicine (1997), Article 10(2) states:*

  "Everyone is entitled to know any information collected about his health. However, the wishes of an individual not be so informed shall be observed."

Outline

- *Good reasons to acknowledge an <u>interest</u> in not knowing*
- *An autonomy perspective is a partial picture*
- *An autonomy perspective can be counter-productive*
- *Preferable to see any RNTK as an aspect of privacy interests*
- *Inform our policy, professional and legal responses to disclosure dilemmas*

Autonomy as a partial picture: unspoken assumptions

- Is there a timely and effectively-informed opportunity to say No?
- How far does a person know there is something to know?
- Is anticipatory refusal even valid or meaningful?
- (Non) disclosures ripples through generations – multiple interests
- Wertz and Fletcher (1991):

> *“[T]here is no way…to exercise the choice of not knowing, because in the very process of asking ‘Do you want to know you are at risk..?’, the geneticist has already made the essence of the information known.”*

RNTK: so what's at stake and what's the 'harm'?

- The removal or diminution of (unfettered) choice?
- The usurpation of decision-making?
- Is there a violation when there is no prior expressed view?
- An invasion of the private sphere?

Not knowing and the private sphere

- *Privacy as a sphere of separateness from others (Laurie 2002, 2014)*
  - Informational privacy (the fallacy of privacy as ‘control’)
  - Spatial privacy (the recognition of psychological separateness)

- <u>Approaches with unsolicited information are a morally and socially significant act</u>
- The act of disclosure has moral meaning and is a *potential* invasion of privacy
- Decisions to (not) disclose are both subject to charge of paternalism

So what?

- An understanding of feelings of violation, even absent autonomy
- A recognition of instrumental or consequential value in not knowing (identity/insurance)
- A presumption of inviolability, which can be rebutted…
- The primacy of individual interests, which are never absolute…
- The nature and degree of importance of reasons to disclose:
  - cure; treatment; severity; likelihood; further intervention; advance decision; knowledge of person; preparedness; reproductive choice; further action from family family…etc

Genetic information and possible claims

- **Article 29 Data Protection Working Group (2004):**

"To the extent that genetic data has a family dimension, it can be argued that it is 'shared' information, with family members having a right to information that may have implications for their own health and future life."

Genetic information and possible claims

But the Group continues: “The precise legal consequences of this argument are not yet clear. At least two scenarios can be imagined.

One is that other family members could also be considered ‘data subjects’ with all the rights that flow from this.

Another option is that other family members would have a right of information of a different character, based on the fact that their personal interests may be affected.

However, in both scenarios further options and conditions would have to be considered to accommodate the various conflicts that are likely to arise between the different claims of family members, either to have access to information or to keep it confidential.”

Human rights, confidentiality and duties of care

- *ABC v St George's NHS Trust et al* (2015, High Court; 2017 appeal)
  - Father murders mother leading to family therapy
  - Father diagnosed with HD and denies permission to inform pregnant daughter
  - Grandchild born and daughter discovers accidentally father's diagnosis
  - Daughter also tested +ve for HD; sues for failure to disclose to her

- Duty of care in negligence:
  - harm is reasonably foreseeable
  - defendant is in a relationship of proximity to the claimant
  - it is "fair, just, and reasonable" to impose a duty in the circumstances

Duty of confidence v Duty of care ?

- **Duty of confidence in law is not absolute**
- **Exceptions include consent, patient’s interest, and public interest**
- **“Public interest” is vastly under-developed in law, but…**
  - ***it is not a percentage game, i.e. more than 50% of society likely to benefit***
  - ***it is not in any sense a qualitative measure, i.e. ‘public’ is diverse as are interests at stake***
  - ***there is currently no ‘overriding’ criterion, i.e. that the public interest must be overwhelming***
  - ***it need not even be directed at members of the public, e.g. effective disposal of an offender***
  - ***So…***
- **“Public interest” is also a policy device, but it does not impose duties to disclose, merely discretion that can be justified and so avoid liability.**

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Policy and professional implications

- Challenging the trend in research feedback policies?
- Re-enforcing non-intervention policy in neonatal screening?
- Non-invasive prenatal testing – who speaks for the fetus?

Thank you for your attention

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