

ARTs and the search for regulatory legitimacy

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Regulatory legitimacy

Procedural legitimacy

- The *form* of decisions
- Transparency
- Accountability
- Acting intra vires

Science & Tech Select Committee (UK)

‘The HFEA’s decision ... went beyond the scope of its own public consultation. It is vital that the public are taken along with decisions of such ethical importance.’



Regulatory legitimacy

Normative legitimacy

- The *content* of decisions

Challenges to normative legitimacy

- Regulatory disconnection
- Autonomy vs public participation
- Value pluralism

‘Descriptive disconnection’

‘the problem is that the covering descriptions employed by the regulation no longer correspond to the technology or to the various technology-related practices that are intended targets for the regulation.’

— Roger Brownsword

‘Normative disconnection’

‘the problem is that the technology and its applications raise doubts as to the value compact that underlies the regulatory scheme – for example, because a known technology is now being applied for a different and questionable purpose or because a new technology raises questions of principle or policy that are not clearly settled by the regulatory scheme. ... the mismatch is one of moral fit.’

Embryo splitting

- HART Act, Schedule 1
- Prohibited actions
- Artificially form, for reproductive purposes, a cloned embryo. For the purposes of this item, a cloned embryo is not formed by splitting, on 1 or more occasions, an embryo that has been formed by the fusion of gametes.

- ACART's advice to you is that embryo splitting is not clinically relevant and that, at present, no action needs to be taken as it cannot proceed in the absence of guidelines.
- If, in future, embryo splitting should become clinically relevant, ACART will review this position and provide further advice to you.

Should embryo splitting be banned?

- Why is human cloning banned?
- Do these reasons give us a good reason to ban all possible uses of human cloning ...
- ... including embryo splitting with single embryo transfer?

Respect for autonomy vs public participation.



‘there is general support for permitting mitochondria replacement in the UK, so long as it is safe enough to offer in a treatment setting and is done so within a regulatory framework.’

— HFEA

‘[A]s technology matures, regulators need to maintain a regulatory position that comports with a community’s views of its acceptable use ... direct dialogue with the public has become a key aspect of procedural legitimacy in technology regulation’

— Brownsword and Goodwin



1. Who, for these purposes, is 'the public'?
2. What should they be asked?
3. What weight should be given to their views?

Which 'public'?

'people seeking treatment are in many ways best placed to judge the seriousness of the condition. ... The HFEA needs to find the correct balance between respecting the views of those seeking PGD whilst preventing the use of the technology for purposes which are widely considered to be unacceptable' (HFEA, 2005)

- Likely users of the technology
- Non-users still likely to be affected
- Sufficiently informed people (focus groups, citizens' juries)
- All members of community

How representative are 'representatives'?

There is seldom one single viewpoint representative of Māori concerns any more than there is a likelihood of finding a single viewpoint on matters in any other socio-cultural context.

- ACART, Informed consent recommendations to Minister (2016)

What should they be asked?

- Do you approve of this?
- Would you make use of this?
- Would you permit others to do this?
- Would you provide this?

Respect for choice as a public value

‘The public was largely relaxed about changing the germ line...Their views were largely shaped by the importance they placed on individual and personal choice for parents.’

— HFEA Mitochondrial consultation report

Depth of enquiry

‘an attempt must be made to characterise the moral frameworks used by members of the public ... Simple surveying of public approval or disapproval of technologies and practices is likely to provide a weak basis for justification of any normative conclusions reached’ (Mike King, 2006).

What weight should be given to their views?

Room for sphere of private decision-making?



‘there are certain standards of behaviour or moral principles which society requires to be observed; and the breach of them is an offence not merely against the person who is injured but against society as a whole.’



‘limits of tolerance’
are reached when
feelings of ordinary
person reach a
certain intensity of
"intolerance,
indignation and
disgust".

— Patrick Devlin, *The
Enforcement of
Morals* (1968)

- Sex selection through testing embryos created outside the body should be should be permitted for 'family balancing':
- Disagree: 67%
- Strongly disagree: 43%
- Tend to disagree: 24%
- 'Just over half (52%) say sex selection is an important issue.'
 - 61% of those in favour, 55% of those opposed.

- Arguably don't meet Devlin's 'feelings of ordinary person'
- 'society as a whole' if only 43% strongly disagree with the practice?
- Certainly doesn't back up HFEA's claim that 'the great majority of the public are strongly opposed.'

Pluralistic legitimacy

- Should seek values that are:
- widely (if not necessarily universally) shared,
- reasonably strongly held,
- applied with a degree of consistency across a range of situations.

- Imperfectly theorized agreements (Sunstein)/overlapping consensus(Rawls)
- “Sometimes, in positions of open ethical pluralism, positions will converge such that parties can sign up to an agreed regulatory position (even though the underlying reasons for agreement are varied); here, we have the basis for a workable accommodation of the competing ethical views.” Brownsword and Goodwin

Potential ITA pitfalls

- ‘a broad consensus of the relatively uninvested’
- Short-term solutions and false economy: papering over ethical cracks?