‘Big Picture Bioethics’

- Novel approaches to the ethical/political analysis of health policy generation
- Diverse disciplinary perspectives (political philosophy, bioethics, law, and HPS)
- New bioethics methodologies
- Comparative analyses of policy-making processes and content (Australia and Canada)

Big Picture Bioethics: Liberal Democratic Ideals

Critical examination of policy processes in relation to the following liberal democratic ideals of governance:

- neutrality or impartiality about the good or avoiding the imposition of a particular set of values on a diverse society
- democratic decision-making understood as deliberative and participatory democracy; and
- respect for cultural difference, commitment to removal of oppression, and concern for disadvantaged members of a society

Three Case Studies

- Provision of publicly-funded health services
- Governance of research involving humans
- Regulation of research on human embryos, human embryonic stem cells, and human cloning

Publicly-Funded Health Services

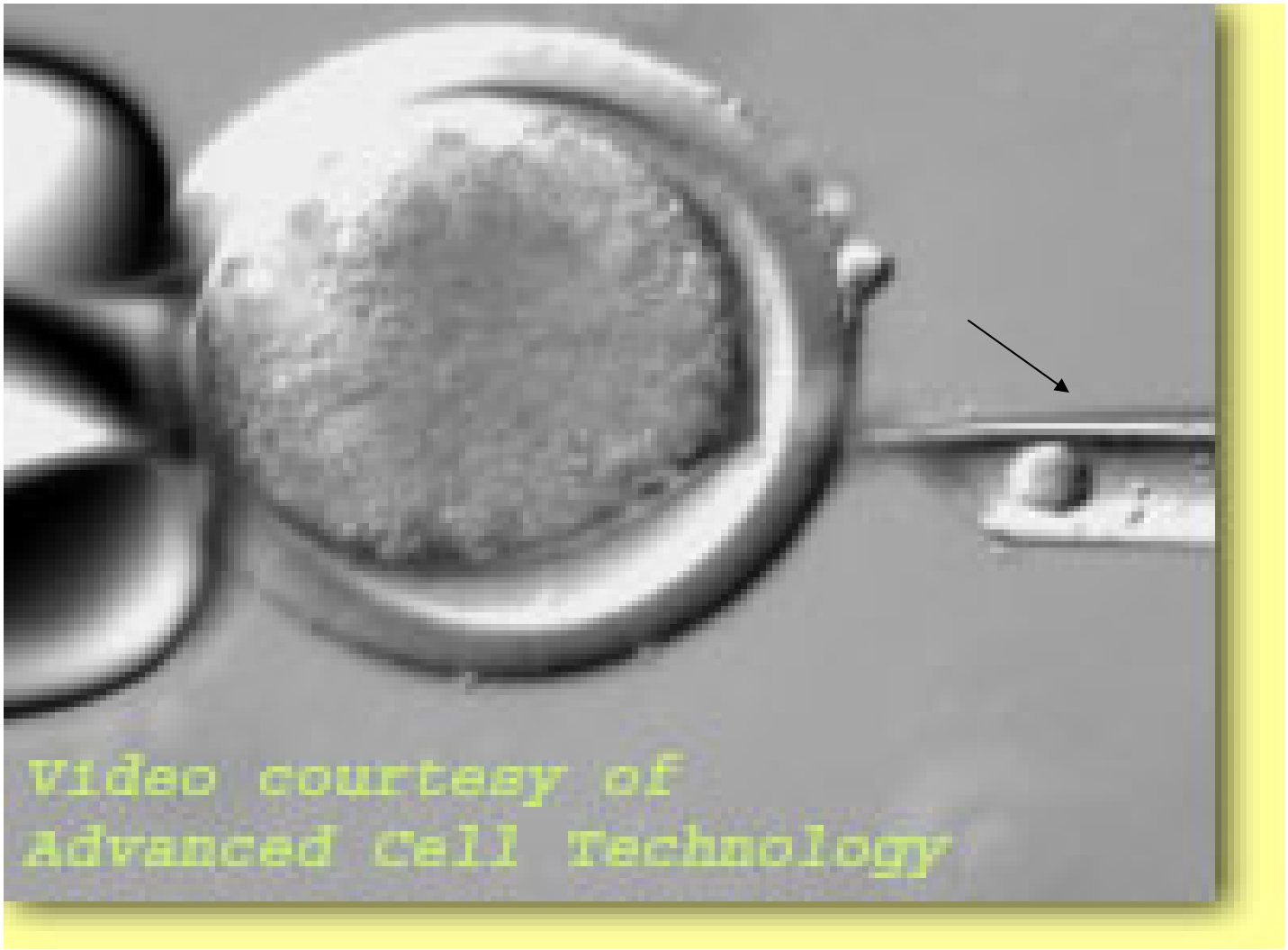
- How are decisions made about access:
  - What should be recognised as legitimate diagnoses and appropriate treatments – e.g CFS, MCS
  - What should be publicly funded – e.g. pharmaceuticals

Research Involving Humans

- How are decisions made about governance:
  - What mechanisms should be used (legislation vs guidelines; independent, institutional, regional)
  - What the content of the regulation should be (e.g. what research is covered, how is research reviewed)

Research on human embryos

- How are decisions made about regulation:
  - Whether to regulate
  - What should be regulated
  - What the means of regulation should be
  - What the content of regulation should be


Video courtesy of
Advanced Cell Technology

Australia/Canada – Snapshot 1998

Australia

Publicly and privately-funded research: In Victoria, South Australia, and Western Australia, state legislation permits licensed research on 'spare' IVF embryos. Different positions on cloning for research.

Publicly-funded research: In all other states and territories, research on 'spare' IVF embryos is permitted in accordance with NHMRC guidelines. Creation of research embryos is prohibited.

Canada

Publicly-funded research: Research on 'spare' IVF embryos is permitted; Creation of research embryos is prohibited.

Privately-funded research: No limits on embryo research.

Australia: 1998 - 2004

- 2001: House Standing Committee on Legal and Constitutional Affairs recommends national legislation for cloning and stem cell research and 3-year moratorium on research cloning.
- Sept. 2002: House passes *Research Involving Embryos and Prohibition of Human Cloning Bill*.
  - Research on ‘spare’ embryos created before April 5, 2002 to derive and study hESC lines and research on existing lines is permitted.
  - Creation of embryos for research and cloning are prohibited.
- Dec. 2002: *Research Involving Human Embryos Bill* and *Prohibition of Human Cloning Bill* pass in Senate and come into force.

Canada: 1998 - 2004

- March 2002, CIHR Stem Cell Guidelines
  - Research on ‘spare’ embryos to derive and study hESC lines and research on existing lines is permitted
  - Creation of embryos for research and cloning are prohibited
- May 2002, *Bill C-56 An Act respecting assisted human reproduction* is introduced (dies on the Order paper)
- Oct. 2003 *Bill C- 13 An Act respecting assisted human reproductive technologies and related research* passes in the House (dies on the Order paper)
- March 2004, *Bill C-6* passes in the Senate and receives Royal Assent

Australia/Canada – Snapshot 2004

Australia

- *All research regardless of source of funding*:
  - Creation of *'research'* embryos is prohibited;
  - Research use of '*spare*' embryos to derive and study hESC lines is permitted with a license on embryos created before April 5, 2002*;
  - Comprehensive ban on cloning.

Canada

- *All research regardless of source of funding*:
  - Creation of *'research'* embryos is prohibited;
  - Research use of '*spare*' embryos to derive and study hESC lines is a controlled activity;
  - Comprehensive ban on cloning.

U.K./U.S. – Snapshot 2004

U.K.

- *All research regardless of source of funding*:
  - Research to derive and study human embryonic stem cell lines from ‘spare’ or ‘research’ embryos is permitted with a license.
  - Cloning for research purposes is permitted; cloning to produce children is prohibited.

U.S.

- *Publicly-funded research:*
  - Moratorium on embryo research continues;
  - August 9 2001, research limited to existing hESC;
  - August 9 2004, only 22 eligible hESC lines.
- *Privately-funded research:* No limits on embryo research, hESC research or cloning research.

Australia/Canada/U.K./U.S., 2004

- In Australia, Canada and the UK, there is no public/private distinction. In the U.S., public/private divide is well entrenched.
- In Australia, Canada and the UK, embryo research is a licensable activity. In the U.S., embryo research is not permitted with federal public funds, but may be permitted with state funds in some states (NJ, CA, MA) and is permitted in the private sector.

Australia/Canada/U.K./U.S., 2004

- In Australia and Canada, the creation of embryos for research is prohibited. In the UK, it is permitted. In the US, it is not permitted with public funds.
- In Australia and Canada, there is a comprehensive ban on cloning. In UK, cloning for research is permitted. In the U.S., cloning is not permitted with public funds and is legally prohibited in some states.

Why the similar policy outcomes in Australia and Canada?

- core values
- health care systems
- mechanisms for the governance of health research
- understanding of “in the public interest”
- commitment to public consultation process

Both jurisdictions say. . .

- The public interest is of paramount importance in the development and implementation of comprehensive and coherent public policy.
- Governments have a *duty* to act in the public interest.

Both jurisdictions say…

Public consultation is important in the development and implementation of public policy because:

- It elicits the diverse social values of multi-cultural communities
- It identifies the range of interests held in the community

This can help in the identification of what the public wants (whether or not it is in the public interest)

This can help in the identification of what is in the public interest (irrespective of what the public wants)