

Strengthening science through regulation

– lessons from the UK

Dame Suzi Leather
Chair, HFEA

Who has an interest?

Patients

Public

Donors

Faith groups/special interest groups

Prospective patients

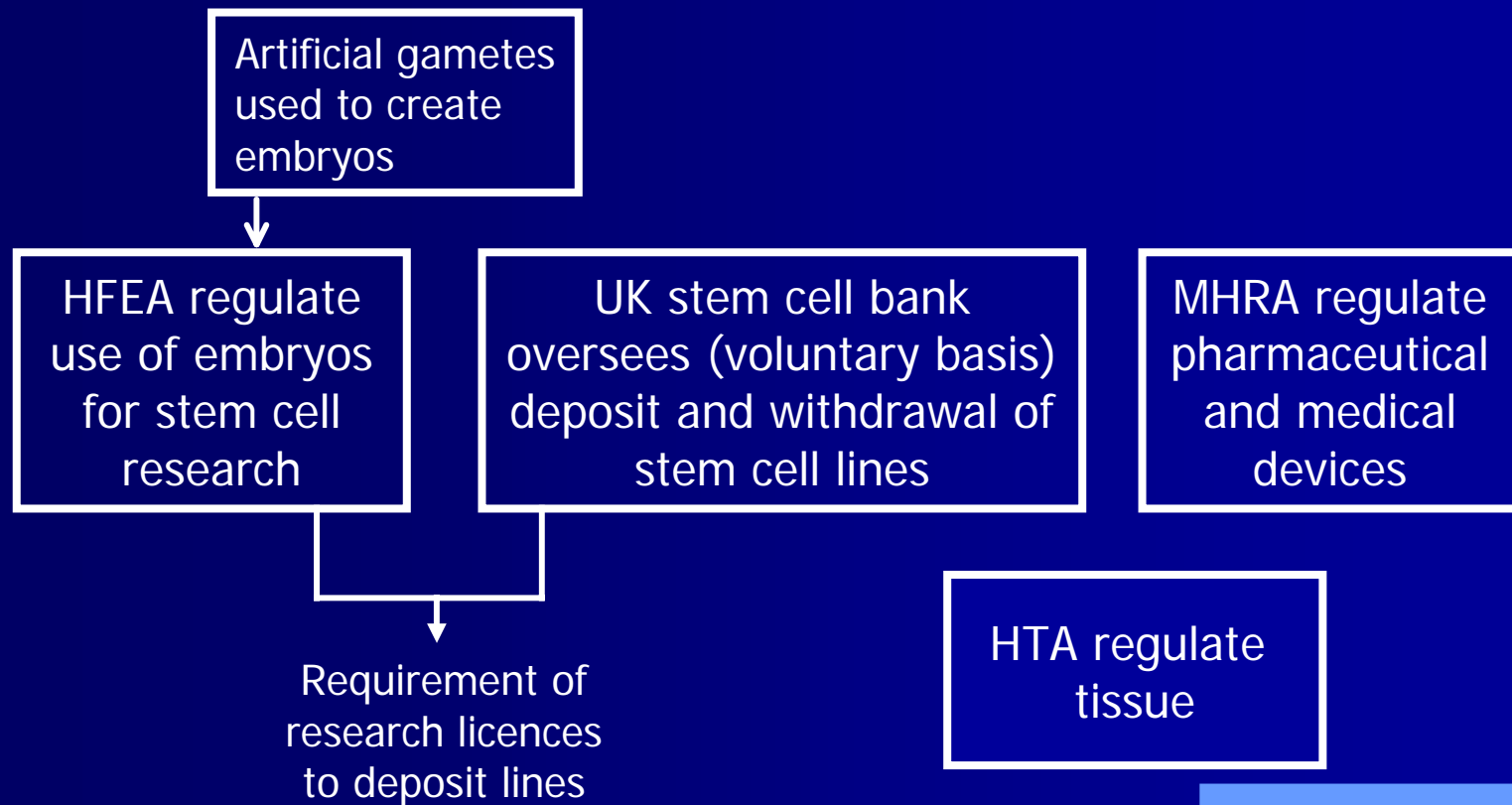
Future Generations

Scientists

Clinicians

Society / Parliament

The regulatory framework



Public attitudes – major study

- One in three associate embryo research with finding cures for diseases or stem cell research
- Benefits of embryo research seen as outweighing risks by 43%.
- 73% believe embryo research can improve quality of life of future generations with inherited disease

Risk and ethics

- 46% believe embryo research poses risk to future generations
- 70% think consequences of embryo research unknown
- 1 in 3 believe it is tampering with nature and therefore unethical
- Half believed it will lead to human cloning

Regulation and trust

- UK regulator most trusted to give honest information on embryo research and to make decisions
- Media and government least trusted to give information
- Honesty, openness, and transparent system are qualities public say give them trust in the system for research

The chain of consensus

Science

Regulatory
Framework

Society



progress

“The regulatory environment is arguably the single most important factor underpinning the global prominence of UK Stem Cell research”

Report of the UK stem cell initiative, 2005

Challenging consensus: implications of Hwang case

- Undermines public confidence and trust in science
- Raises a number of questions:
 - Scientific fraud: validity of research findings from projects
 - Reliability of peer review
 - Ethical concerns over egg donation
 - Regulation of international collaboration?

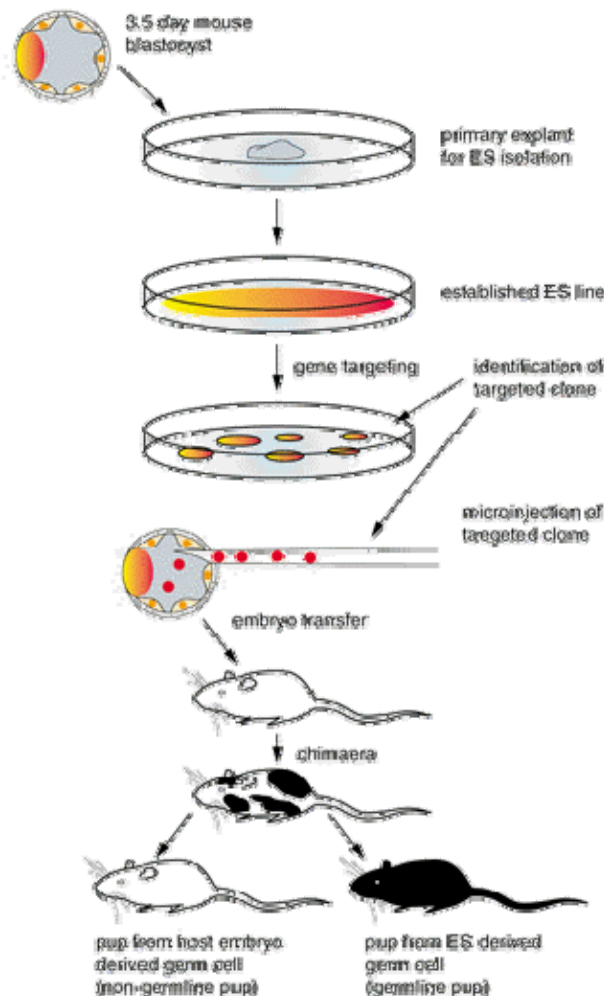
Challenging consensus: looking to the future

- sudden advance
- 'yuck' issues
- definitions
- elitist medicine

Challenging consensus – source and supply of eggs

- CNR research needs thousands of eggs
- Research vs treatment
- The dangers of coercion
 - direct and economic
- International sourcing - Can we allow a 'lowest common denominator' approach?

A framework for the future? – the Chimera example



- Chimeras used to test for pluripotency of mouse stem cell lines
- Chimeras could be used for CNR research or to test human embryonic stem cell lines
- How much human DNA makes us human?
- Government have previously said no to chimeras

Securing the future

- Appropriate regulation
- Partnership
- Responsibility
- Consensus