Stem cell dialogue: key findings, conclusions and recommendations

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Objectives

Engage the public and stakeholders on stem cells: policy development

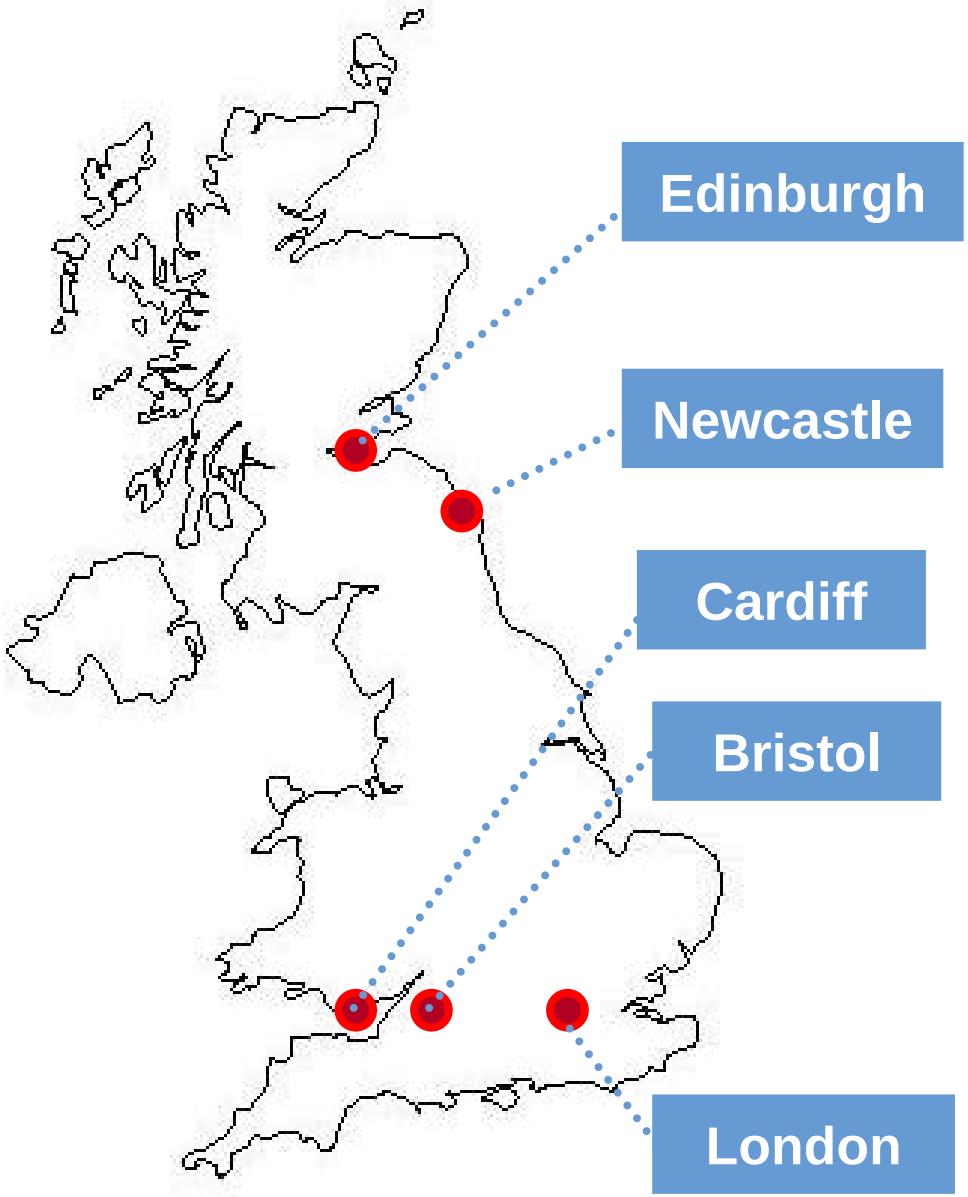
Views and concerns

Raise awareness

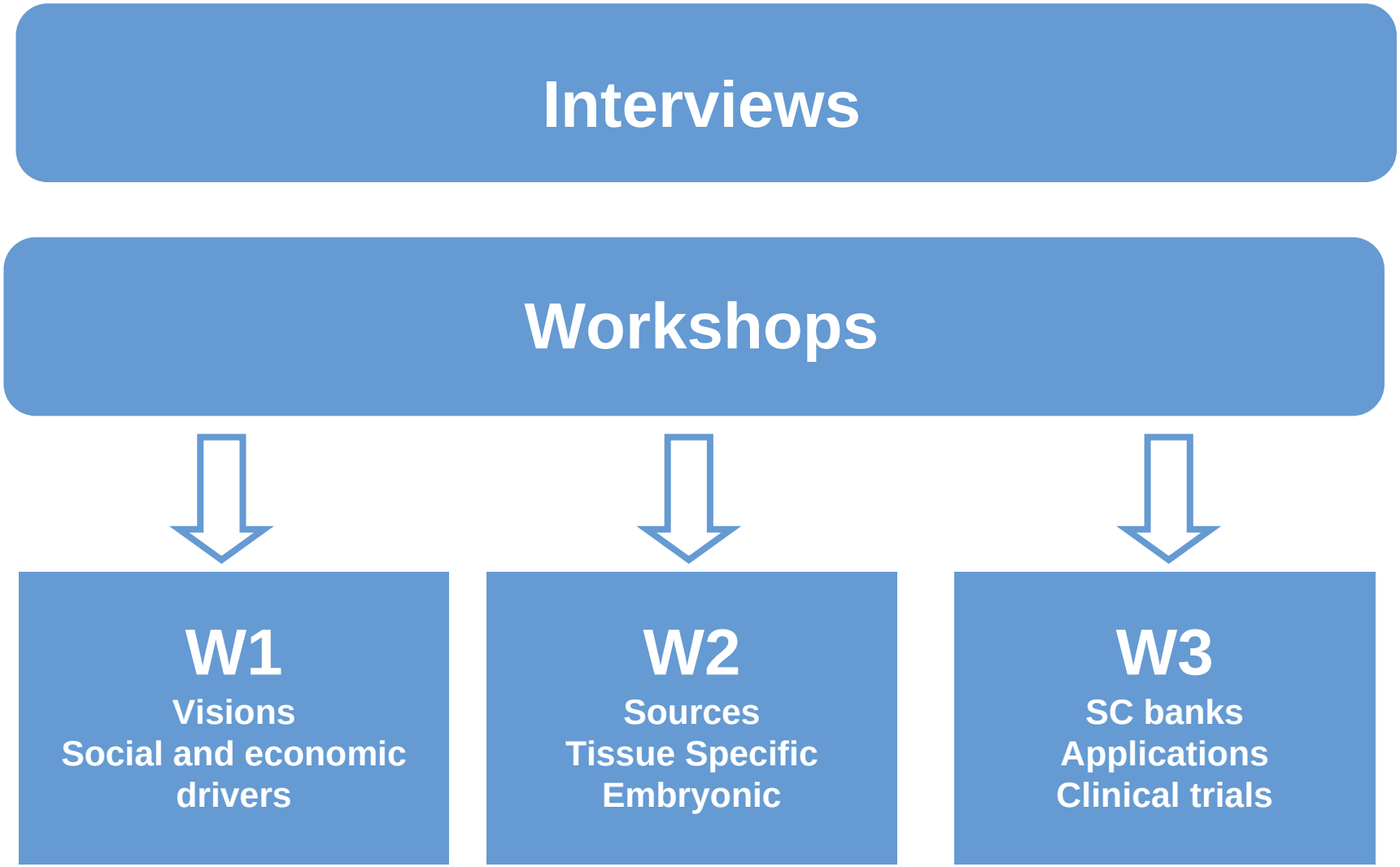
Future dialogue

Approach

- 200 members of public
- 5 deliberative workshops – reconvened 3 times
- 49 stakeholders
- Depth interviews
- Q methodology
- Framework analysis



Issues discussed



Key findings

Value of basic and applied research

High levels of support - but conditional

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What is a serious disease

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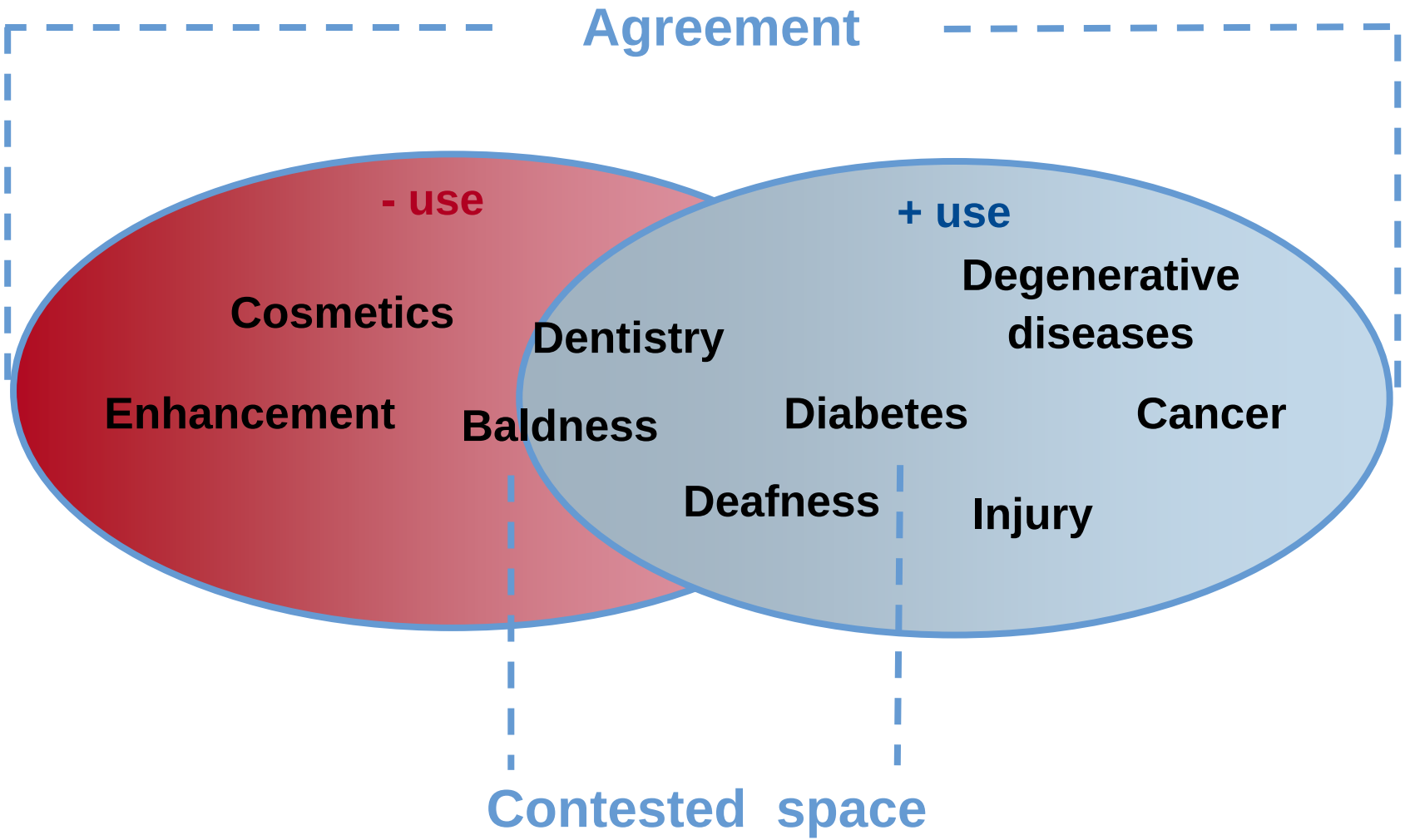

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Plurality of perspectives

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Adult and embryonic

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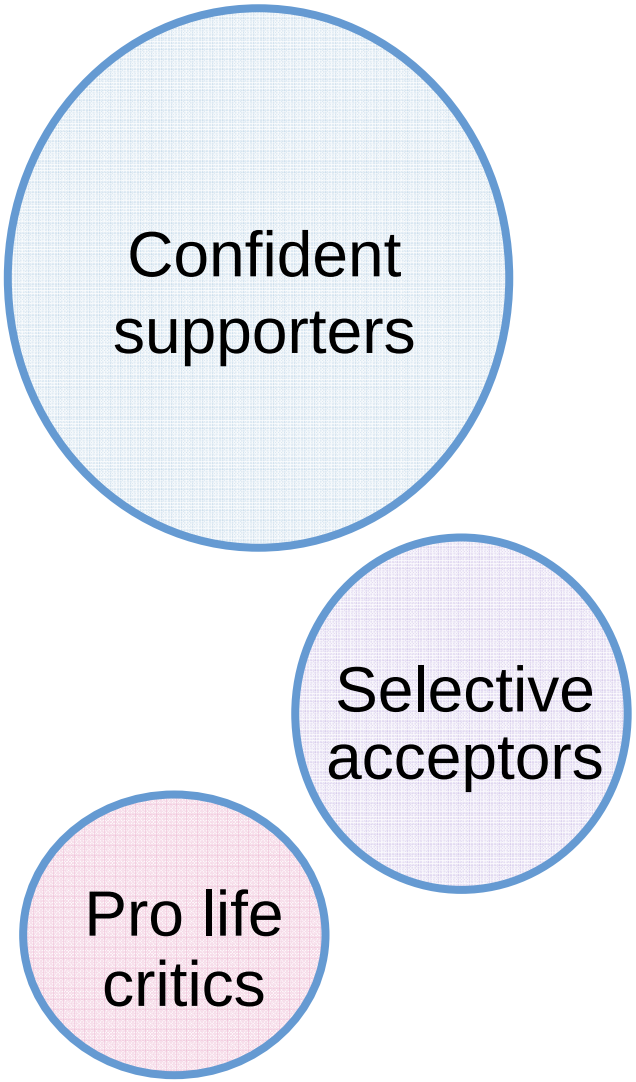
People valued basic research

Ethics of stem cell sources



- Ethical concerns across a range of sources
  - Embryos
  - Protection of women
  - Rights of patients
  - Clinical concerns

Investment: commercialisation and public value

Investment needed for clinical applications

Gap (and opportunity) for funding between public, private and charitable sector

Healthcare pull from NHS

Rainbow coalition for support

Public concerns around private investment

Ends of technology

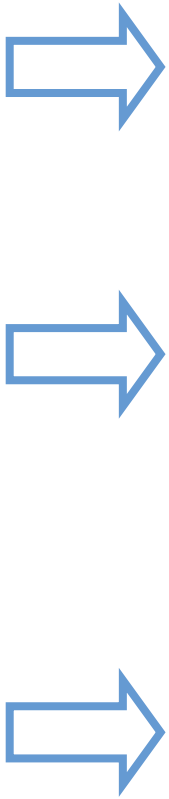
Process: openness, transparency, disclosure

Affordability of treatments

Governance

Hard infrastructure

systems and institutions that control of science - government and regulators



Tension between permissive legislation and tight regulation

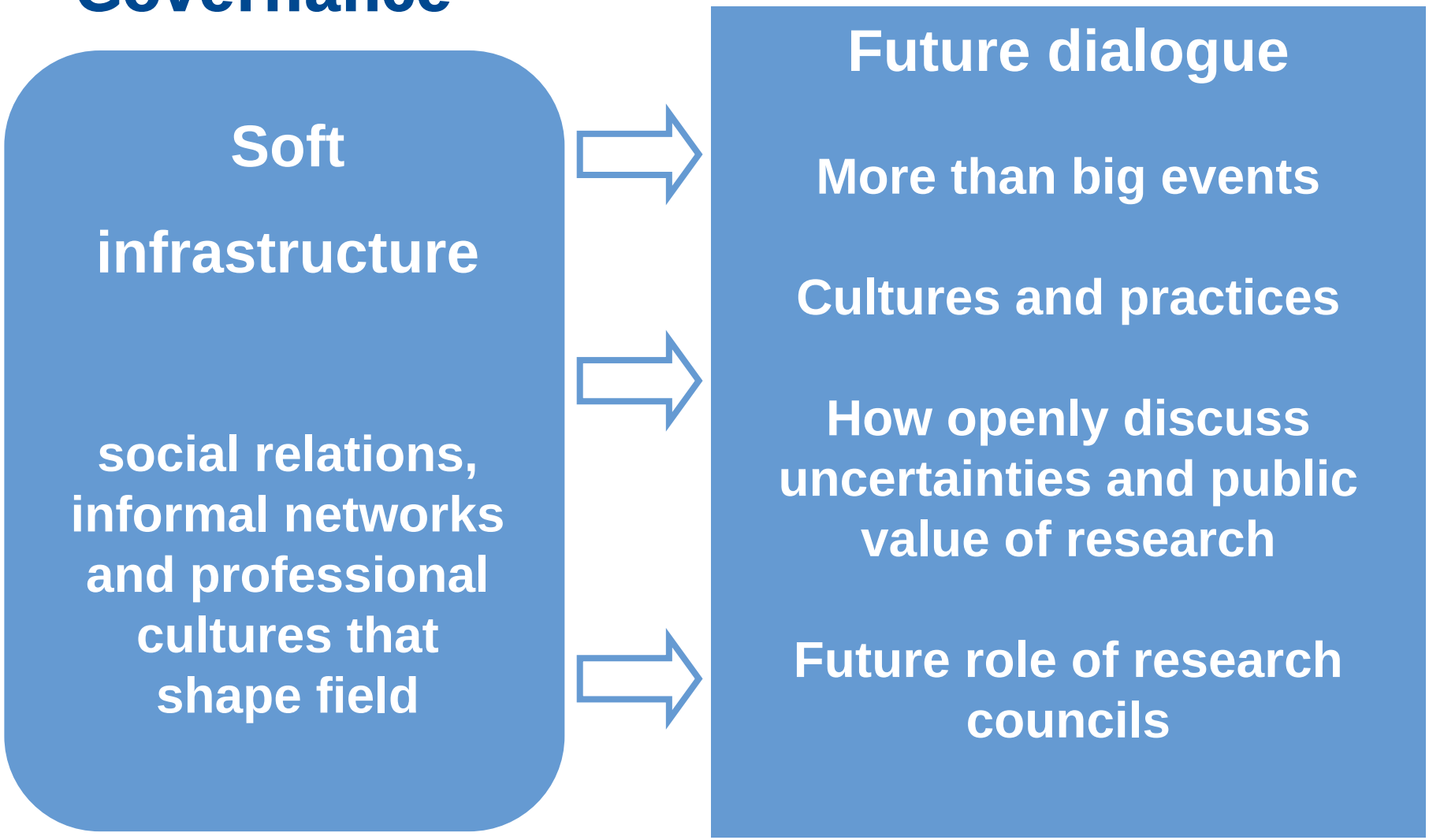
However, important for provenance stem cell lines – ethical and safety

Competent authorities as science develops Therapeutic or device HTA, MHRA, HFEA, EMEA

Informed consent

Risk and clinical trials

Governance


Soft
infrastructure
social relations, informal networks and professional cultures that shape field
Future dialogue
More than big events
Cultures and practices
How openly discuss uncertainties and public value of research
Future role of research councils

Key conclusions and recommendations

1. Funding

- Conditional support for all avenues of stem cell research
- Priorities on basic and translational research
- Clinical priority - treatments are limted

2. Ethical approval ES cells

- Reflect the views of public and donors
- Necessity and how 'serious' disease is defined
- Difficult to establish firm guidelines on donor consent in future

Key conclusions and recommendations

3. Health and wealth opportunities

- Greater investment and coordination between public and private sectors to achieve this goal
- Charity campaign - raise resources and profile

4. Private sector

- Concerns: means and the ends of research
- Use for socially valued purposes
- Need to disclose information in the public interest
- Research councils and universities mindful when commercialising research

Key conclusions and recommendations

5. Governance

- Legislation supported, regulation viewed as cumbersome by certain groups
- Coordination between regulators in move to clinical practice
- Governance clinical trials - experimental therapies with patients

6. Future dialogue

- Focus on the cultures and practices of research
- Uncertainties in stem cell science should be communicated
- Key issues to look out for: private banking of cord blood and Induced Pluripotent Cells