Human bodies:
donation for medicine and research

Introduction and overview of the report

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Why did we produce this report?

- Regulatory landscape has changed since *Human tissue: ethical issues* report (1995)
- Demand for bodily material remains high
- How it is obtained raises ethical questions
- Different practices in different areas of donation
- A broader question needed answering: *How far should society go in attempting to encourage or facilitate the donation of bodily material?*
- We take a **comparative** approach and focus on issues for the **donor**

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How did we produce this report?

- 12 Working Party members
- Met Jan 2010 to May 2011
- Meetings with regulators, researchers, clinicians
- Public consultation: 180 responses
- Workshop with 43 recruited members of public

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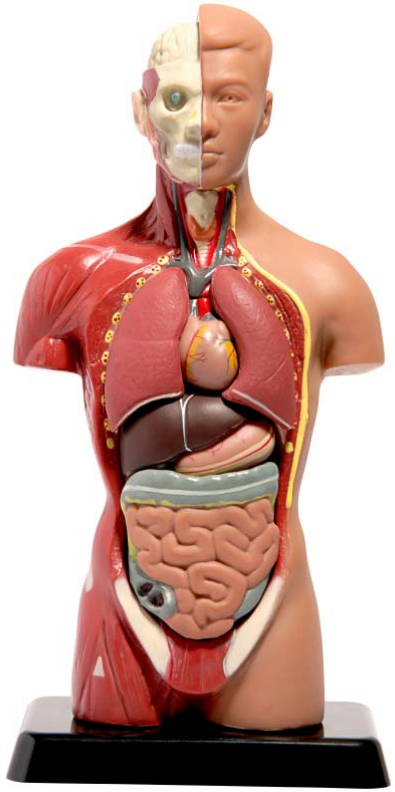
What bodily material can be donated?

- Blood and blood products
- Solid organs
- Tissue, including bone, skin, arteries and corneas
- Eggs, sperm, embryos
- Whole bodies after death
- Whole living bodies as ‘healthy volunteers’ for clinical trials



After death and/or during life

For treatment and/or research

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Regulation of donation in the UK

- Oversight by HTA or HFEA
- Consent required from donor
- Donation of bodily material for treatment:
  - no payment allowed, although ‘egg sharing’ permitted
  - full expenses reimbursed for living organ donors, but cap of £250 for egg and sperm donors
- Donation for research: payment not illegal
- Whole body for medical education: funeral expenses
- Healthy volunteers in clinical trials: payment allowed

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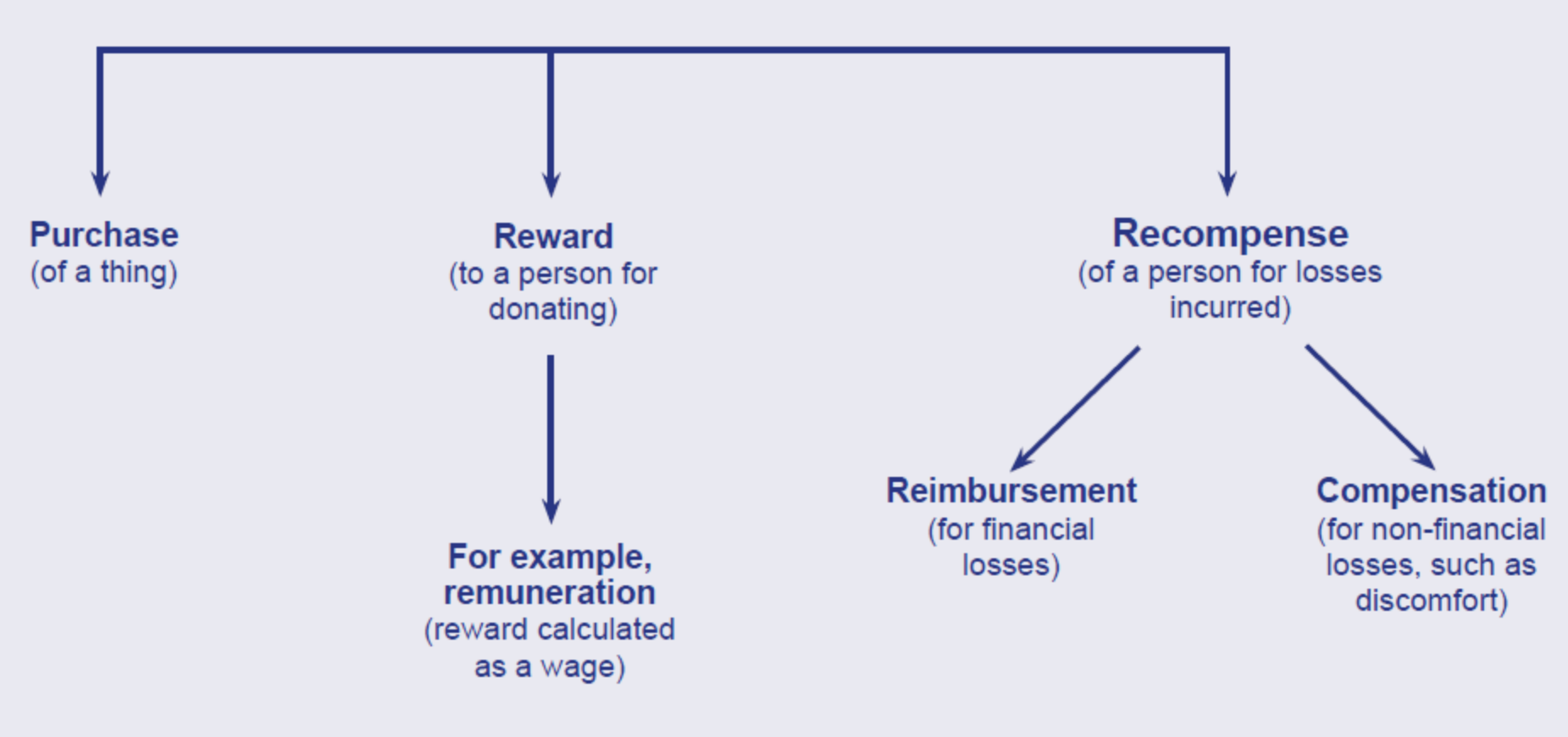
Payment terminology



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International comparisons

- International consensus that paying for organs is inappropriate, but organ trafficking persists
- Spain and Belgium have 'opt-out‘ systems for deceased organ donation
- Iran permits payment for living organ donors though national system
- Many USA states have no restrictions on paying for eggs or sperm

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Supply and demand

High demand for bodily material due to:

- increasing possibilities for using bodily material
- high levels of obesity, diabetes, alcohol consumption
- public expectations of medical science

Ways of reducing demand:

- Public health initiatives
- Research into alternatives

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Possible ways of increasing supply

- Encouraging individuals to donate
  - e.g. information, recognition, removing barriers, offering incentives
- Changing consent rules
  - e.g. opt-out, prompted or mandated choice systems for organ donation
- Improving organisational structures
  - e.g. co-ordinated systems for donation, more transplant professionals

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Our findings

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When is donation a public vs a private matter?

- ‘Good health of society’ is strong ethical argument for meeting demand for bodily material
- The state has an obligation to promote good health – applies to reproductive material as well
- Research is of vital public interest, including private/commercial – suggest benefit sharing partnerships
- Property rights over bodily material – distinguish between rights of control and rights to income
- National self-sufficiency – good aim but cannot alone justify unethical actions

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Our ethical framework

- Altruism should continue to play a central role
- This does not necessarily exclude other approaches such as reward in some circumstances
- There are two kinds of action:
  - altruist-focused interventions
  - non-altruist-focused interventions (these need closer scrutiny)
- The welfare of the donor and any potential threat to the common good should be the most important considerations
- We reject the sale and purchase of bodily material

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Our ethical framework cont…

- Donation for research purposes differs in important ways from donation for treatment purposes
- Trust and respect play an essential part in systems in which people will be willing to donate – good governance
- Donor's wishes are central – consent important
- We suggest use 'authorisation' or 'willingness to donate' instead of consent for deceased donation

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‘Intervention Ladder’ for encouraging individuals to donate

Rung 6: financial incentives

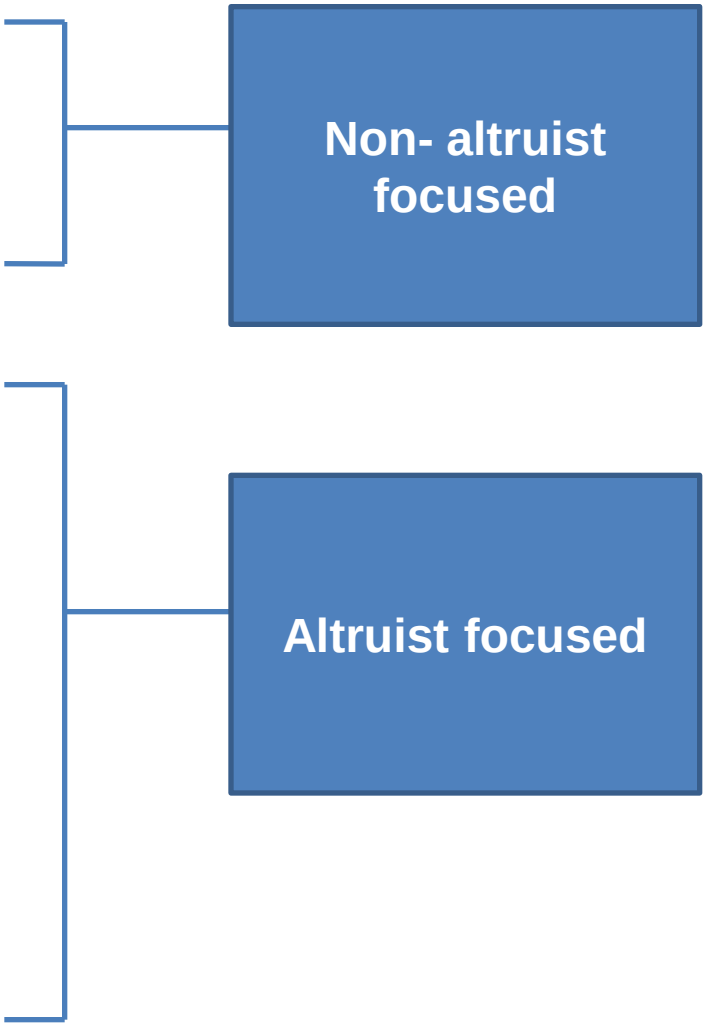
Rung 5: benefits in kind linked with donation

Rung 4: interventions as an extra prompt or encouragement

Rung 3: removing barriers and disincentives

Rung 2: recognition of altruistic donation

Rung 1: information about the need for the donation



Recommendations in brief

Organs

- Demand for organs should be used to add weight to public health campaigns
- Suggest pilot scheme for paying for funeral expenses of organ donors
- Option for donation for research and option to say ‘no’ should be clearer on Donor Register
- More research needed on ‘opt out’ system
- Support mandated and prompted choice systems for prior authorisation of deceased donation

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Recommendations in brief…

Egg and sperm donation

- Lost earnings should be fully reimbursed
- National or regional egg donation infrastructure
- Pilot scheme offering payment for egg donation for research purposes
- UK practitioners should take more responsibility for standards in referral clinics abroad
- WHO guidance to protect egg donors from exploitation

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Recommendations in brief…

Tissue donation for research

- Good governance systems are essential
- Donors should be treated as partners in the research
- Once donated, bodily material should be regarded as a public good
- Appropriate for commercial companies to make additional contribution to the costs of tissue banks

Volunteering for clinical trials

- Volunteers should be treated as partners in the research
- National database of volunteers to limit over-volunteering

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