

Breakout session 2: Donation for research

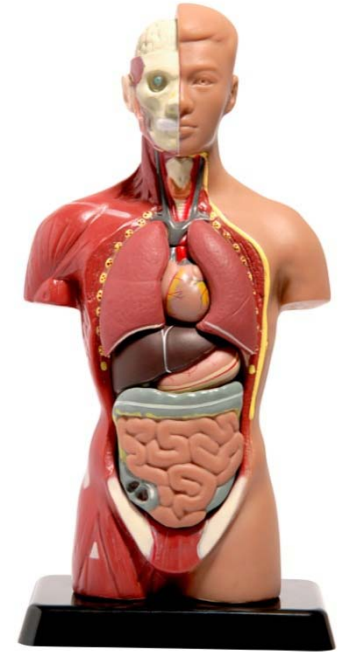
Tissue and organ donation

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What is donated?

- Blood, diseased tissues and normal tissue are commonly used in research
- ‘Left-over’ from an operation or specifically donated (during life or after death)
- **Increased demand** for tissue in research
- **People very willing to donate for research:**
 - Study: only 1% refused to donate
 - 500,000 people have donated to UK Biobank

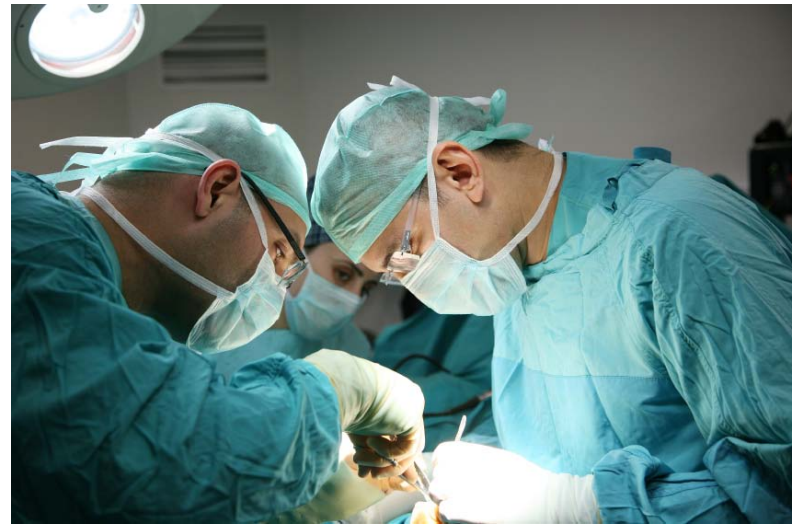


Problems with supply

- Current policy:
 - Usually require valid **consent** from donor: ‘specific’ or ‘generic’ (‘blanket’ ‘tiered’ ‘broad’)
 - Need **HTA-licensed** premises and **REC** approval
- Researchers report problems in accessing material due to problems in the **system**:
 - inadequate systems for obtaining **generic consent**
 - **bureaucracy** of regulations and within organisations
 - lack of willingness to **share** samples

Successes

- Research funders' position: **generic consent** should always be sought
- Tissue banks allow **generic consent** to be sought for use in many projects
- Integration of **consent** procedures in clinical practice:
 - information on surgical consent form
 - nurses who seek consent for research
- **Networks** established



Ethical considerations

We believe:

- Research and potential future health benefits are of vital **public interest** (including commercial sector):
 - new treatments and diagnostics for all
 - reducing need for tissue and organs in future
- People will donate within a system that they **trust**
- We support current emphasis on **consent** of donor
- Ethical imperative to make **efficient use** of donated tissue
- **Sharing the benefits** of research should take place in a wider context – not to individuals

Recommendations: deceased donation

- Option of donating organs and tissue after death for research should be routinely available:
 - clearer in ODR information
 - pilot: approach families considering deceased donation
- Demand for better infrastructure should be explored



Recommendations: living donation

- Endorse research funders' aim to develop guidance on seeking **generic consent** – should include consideration of **broad consent**
- Research funders should increase **public awareness** of importance of donated tissue to research
- Commercial companies that benefit from freely donated material should contribute to **costs of tissue banks**