

# Workshop on human bodies in medicine and research

## Agenda for the day

Timing	Content
9.30 – 10.00	Arrival and registration
10.00 – 10.15	Welcome and introduction
10.15 – 10.45	Initial discussion of donation
10.45 – 11.25	Introduction to the different types of donation
11.25 – 11.40	Break
11.40 – 12.30	Discussion of issues around supply and demand
12.30 – 1.15	Lunch
1.15 – 2.30	Discussion of issues around consent and Control
2.30 – 2.45	Break
2.45 -3.45	Discussion of issues around incentives and recognition
3.45 -4.15	Summing up
4.15 – 4.30	Close

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# Workshop on human bodies in medicine and research

## Start of day questionnaire

Thank you for coming today. Before we get started we just want to get a couple more pieces of information about you and to get an initial impression of what you think about the donation of human bodies in medicine and research. Please answer these questions as best you can from your existing knowledge.

**Q1. Are you on the organ donor register?**

PLEASE TICK ONE OF THE FOLLOWING

Yes	
No	
Don't know	

**Q2. If you are a blood donor, when was the last time you donated blood?**

PLEASE TICK ONE OF THE FOLLOWING

Less than 6 months ago	Between 6 months and 1 year ago	Between 1 year and 2 years ago	Between 2 and 5 years ago	More than 5 years ago	Have never donated blood

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**Bodily material is used for many purposes in medicine and research. Organs from living or deceased donors can be used in transplants or research, sperm or eggs can be donated to help people have a child, blood can be donated for use in medical treatment, and complete bodies donated during life or after death can be used for medical research. The next set of questions refers to all different types of donation.**

**Q3. Sometimes the demand for bodily materials for use in medicine and research may be greater than the supply available through donation. How important do you think it is to take steps to increase the amount of donation to meet the demand for bodily materials? Would you say it is.....?**

PLEASE TICK ONE OF THE FOLLOWING

<b>Not at all important</b>	<b>Not very important</b>	<b>Neither important nor unimportant</b>	<b>Somewhat important</b>	<b>Very important</b>

**Any comments:**

**Q4. Who do you think should have control over what happens to donated material e.g. what it is used for, who it is given to etc.**

PLEASE TICK ONE OF THE FOLLOWING

The person who donated it	
The family of the person who donated it	
The doctor/researcher who receives the donation	
The government	

**Any comments:**

**Q5. Please indicate how much you agree or disagree with the following statements:**

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Disagree</b>	<b>Strongly agree</b>	<b>Don't know</b>
<b>I think people have a duty to donate their bodily material (eg blood, organs) to help others</b>						
<b>I think that people should receive some kind of recognition for donating their bodily material to help others, eg inclusion on a public memorial or a letter of thanks</b>						
<b>I think that that people should receive extra benefits for donating their bodily material to help others, eg priority for an organ if they needed one in future, or free fertility treatment</b>						
<b>I think people should be paid cash to donate their bodily material</b>						

**Any comments:**

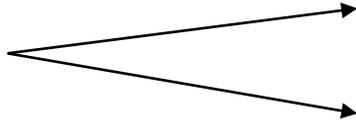
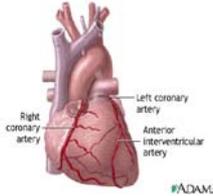
# DONATION FLOW CHART

## BODILY MATERIAL

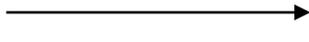
## FROM DEAD OR ALIVE PERSON?

## PURPOSE

Organs  
e.g. heart,  
kidney



Dead

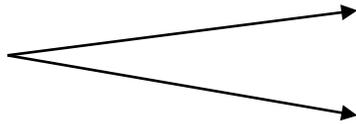
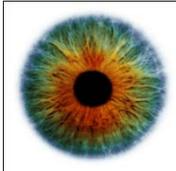


Prolong, save and enhance life

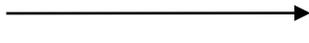
Alive



Tissue  
e.g. cornea,  
bone, skin



Dead

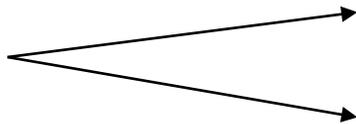


Prolong, save and enhance life

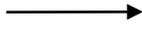
Alive



Blood



Dead



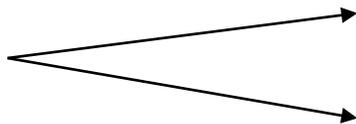
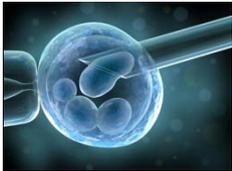
X

Alive

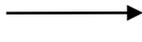


Prolong /save life

Gametes  
e.g. sperm,  
eggs



Dead



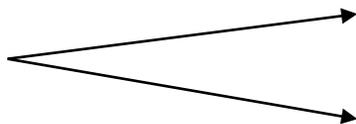
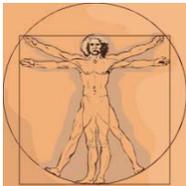
X

Alive



Create life

Whole  
body



Dead



Training, research

Alive



Research

# TYPES OF DONATION

## **After death**

- Tissue donation for life-saving treatment, eg skin to treat serious burns victim
- Whole organ donation for life-prolonging transplant, e.g. heart, kidney, liver
- Tissue donation for life-enhancing treatment, eg cornea to restore sight
- Organ or tissue donation for a publicly-funded research project on the causes of cancer
- Organ or tissue donation for a pharmaceutical company research study on a new anti-cancer drug

## **During life**

- Blood donation for life-saving treatment eg during an emergency operation
- Live organ donation for life-prolonging transplant e.g. kidney or lobe of liver
- Egg or sperm donation for fertility treatment
- Donation of 'left over' material removed during an operation for a publicly-funded research project on the causes of cancer
- Donation of 'left over' material removed during an operation for a pharmaceutical company research study on a new anti-cancer drug
- Taking part in a clinical trial run by a pharmaceutical company to test the safety of a new cancer drug

AFTER DEATH: Tissue donation for life-saving treatment, eg skin to treat serious burns victim

AFTER DEATH: Whole organ donation for life-prolonging transplant, e.g. heart, kidney, liver

AFTER DEATH: Tissue donation for life-enhancing treatment, eg cornea to restore sight

AFTER DEATH: Organ or tissue donation for a publicly-funded research project on the causes of cancer

AFTER DEATH: Organ or tissue donation for a pharmaceutical company research study on a new anti-cancer drug

DURING LIFE: Donation of 'left over' material removed during an operation for a pharmaceutical company research study on a new anti-cancer drug

DURING LIFE: Egg or sperm donation for fertility treatment

DURING LIFE: Taking part in a clinical trial run by a pharmaceutical company to test the safety of a new cancer drug

DURING LIFE: Blood donation for life-saving treatment eg during an emergency operation

DURING LIFE: Live organ donation for life-prolonging transplant e.g. kidney or lobe of liver

DURING LIFE: Donation of 'left over' material removed during an operation for a publicly-funded research project on the causes of cancer

## Consent and Control 1 – Jane, Sarah and Marie

### FICTIONAL SCENARIO

- Jane is 29 years old and is married with two children
- Some of her friends have been through courses of IVF treatment in order to have children
- She would like to help other couples to have children and decides she wants to donate her eggs to a local clinic
  
- Sarah is a doctor at a local IVF clinic. She discusses the donation procedure with Jane
- Jane says she will not donate without a guarantee that her eggs will not go to a same sex couples or single women
- Sarah says that this clinic does not allow donors to put any limits on which of its patients their eggs go to. She says that eggs are allocated on a first-come, first-served basis
- Jane does not donate her eggs
  
- Marie is 33 years old and is married
- She and her husband has been trying to have a child for 2 years through various methods of IVF
- Without a donated egg Marie would be unable to attempt IVF and is currently on the waiting list at the clinic
- Jane's donated eggs may have been given to her if she had made the decision to donate

# Consent and Control 1 – Probes

- Overall what do you think about this scenario
- What do you think of the behaviour of the various parties (particularly Jane and Sarah)
- Jane
  - How do you think Jane would feel during the meeting? How do you think she would feel not being able to/allowed to donate if she wants to stick to her beliefs? How much should her feeling be taken into account?
  - Does it make a difference where her desire comes from e.g. religious faith, conviction etc?
- Sarah
  - What do you think of Sarah/the clinic's decision not to allow donors control? Are they right?
  - What level of control should they allow? Total i.e. to discriminate on any basis – sexuality, age, race, nationality, (shoe size)? In particular circumstances e.g. religious conviction. Why in these circumstances and not others (probe list above)?
  - What should Sarah's driving aim be – meeting demand, maintaining the clinics ability to control, a mixture? How do these trade off
- Marie
  - Does Marie's need for an egg influence what is right or wrong in this situation
  - How important should her need be compared to other factors
- Alternatives
  - Would it be better if the situation was reversed – Jane able to stick to her belief, but Marie was part of a same sex couple and was ineligible for the eggs

## Consent and Control 2 – Jamal, Claire, Anushka and Julie

### TRUE-TO-LIFE SCENARIO

- Jamal is 38 and married to Claire who is 36, they have 2 children. Claire has kidney disease and needs dialysis regularly to clean her blood
- Doctors say she will be able to survive for potentially up to a decade, however she will always need dialysis and her quality of life may get worse in the years to come
- Jamal would like to donate a kidney to his wife but is an unsuitable donor
- Anushka is Claire's specialist. Working with other specialists around the country they have set up a 2-way kidney swap, whereby the partners of each of the patients donate to another patient so their partner can receive a donor kidney in return
- Jamal is happy to donate one of his kidneys on this basis
- Julie is 46 and married with 3 children. She is in late stage kidney failure and doctors have said she is likely to die within a year without a transplant. She is part of the 2-way kidney swap, Jamal would be a suitable donor for her, and she has a partner who is a match for Claire
- However just before the transplant is due to take place Julie's partner can no longer donate. Jamal is still eligible to donate to Julie, however Claire will no longer receive a transplant as part of the scheme

# Consent and Control 2 – Probes

- Overall what do you think about this scenario
- Who should get Jamal's kidney? Who has best 'claim' for it
- Jamal
  - What should Jamal do? Should he still donate to Julie if his wife does not receive something in return?
  - Does it make a difference if he knows about Julie? Should he be told? How would that make him feel?
  - What about potential health risks to Jamal? How much does this affect what is right or wrong in this scenario?
- Anushka
  - What should Anushka's driving principle be – to meet demand, to treat patients fairly according to greatest need
  - What is more important – sticking to general principles of treating patients according to need or being pragmatic and trying to meet demand however they can
- Claire and Julie
  - Who should receive Jamal's kidney
  - Does it make a difference if Jamal would **only** give a kidney if his wife receives one?
  - How would Julie feel in this situation

## Consent and Control 3 – Debra, Graham, Gwen and Tracey

### TRUE-TO-LIFE SCENARIO

- Debra and Graham both die on the same day in the same hospital. Debra was 47 and has no living family members. Graham was 33 and married with 2 children
- Gwen is a doctor at the hospital responsible for assessing the potential for donations to be made from recently deceased patients
- Gwen feels that Debra would be an ideal person to donate her corneas and skin. However she can see that Debra was not on the organ donation register
- Without any relatives to consult Gwen is unable to recommend that Debra's tissue be taken for donation
- Gwen also thinks that Graham would be a suitable donor and notes that he is on the organ donation register
- She talks to Graham's widow about the possibility of his organs and tissue being transplanted to others. She explains that several people may benefit from Graham's donation.
- Graham's widow feels it is very important for her husband to be buried and wants his body to be complete when this happens and says she does not want his organs or tissue to be donated
- Gwen does not think it is appropriate to go against the wishes of Graham's widow and the body is released to his widow
- Tracey is 40 and has a painful eye condition which means she is partially blind. A corneal transplant would have a good chance of restoring her vision.
- James is 10 and has come into the local A&E department with serious burns following a fire at his home. A skin graft using donor skin could save his life.

# Consent and Control 3 – Probes

- Overall what do you think about this scenario
- Debra
  - What should happen to Debra's tissue?
- Graham
  - What should happen to Graham's tissue?
  - How important is it that he is a registered organ donor. Does it matter when he registered (before or after marriage etc)?
  - How much should the views of his widow count?
- Gwen
  - What should Gwen do in both these situations?
- Tracey and James
  - How much should Tracey and James's need for a transplant affect these decisions?
  - Is there a difference between their needs?

## Consent and Control 4 – Dwain, Trevor and Rachel

### TRUE-TO-LIFE SCENARIO

- Dwain is 34 years old and requires surgery to remove a cancerous tumour
- Trevor is the surgeon who is going to carry out the surgery on Dwain
- Rachel is a researcher in the hospital. She would like to use some of the tumour that is to be removed in research she is carrying out to study the mechanisms of cancer
- Trevor informs her that she must have Dwain's permission to use the 'left-over' tumour cells, and he does not wish to bother Dwain about this at such a difficult time
- Dwain's tumour is disposed of by the hospital in the clinical waste system

# Consent and Control 4 – Probes

- Overall what do you think about this scenario
- What should happen to Dwain's leftover tumour?
- Dwain
  - Is it important to obtain Dwain's consent to use his leftover tumour?
  - What do you think Dwain would think in this scenario?
  - Does it matter if he would have said no if he had been asked?
- Trevor
  - How would Trevor feel in this scenario?
  - What should he do?
- Rachel
  - How would Rachel feel in this scenario?
  - What should she do?

## Consent and Control 5 – Carl, Daniel, Martin and Katherine

### TRUE-TO-LIFE SCENARIO

- Carl is 12 and Daniel is 18, they are brothers. Martin is 52 and is their father
- Both Carl and Daniel have the same inherited kidney disease.
- When the disease first developed in Daniel the family was screened and Martin was identified as a suitable donor. He happily donated one of his kidneys to Daniel who is now able to live a normal life with no need for dialysis.
- Martin is also a suitable donor for Carl and would like to give him his other kidney. This would leave him with no kidneys and he would have to spend the rest of his life on dialysis.
- Katherine is the doctor treating Carl. She talks to Carl and Martin about the possible donation
- She says that because Martin will have to spend the rest of his life on dialysis she will not carry out the transplant
- She says Carl will have to stay on the register until another suitable donor is found. Until then he will have to remain on regular dialysis

# Consent and Control 5 – Probes

- Overall what do you think about this scenario
- What should happen in this scenario? Who should make the decision?
- Carl
  - How would Carl feel in this situation? Compared to his brother?
  - How much does his need for a transplant influence the rights and wrongs of this situation?
- Martin
  - How much should Martin's desire to donate his kidney be considered in this situation?
  - How much should the impacts on his health be counted? Should people be able to damage their own health in this way? Whose health counts more – Carl or Daniel, both equally?
- Katherine
  - What should Katherine do? Whose interest should she protect? What role should she have – advisor, arbiter?
- Daniel
  - How would Daniel feel in this situation?

**Handout 9 – Incentive and  
recognition scenarios**

## Incentives and recognition 1 – Paul, Dennis and Rupali

### FICTIONAL SCENARIO

- Paul is 26 years old and single. He would like to help people who are struggling to have children and decides he wants to donate his sperm
- He decides to go to a local IVF clinic to find out about the process
- Dennis works at the clinic and he meets with Paul to discuss sperm donation
- He tells Paul that he will be paid £100 for the sperm he donates
- Paul feels that this payment must mean lots of people are donating, just for the money, and decides not to donate
- Rupali is 34. She and her husband have been trying for a baby for several year. They require donated sperm to be able to have a child

# Incentives and recognition 1 – Probes

- Overall what do you think about this scenario
- Paul
  - What do you think of Paul's motives?
  - What do you think of Paul's decision not to donate?
  - Should donors be paid as fair recompense for their donation as with any other commodity, or should people donate only if they feel moved to? What is a fair level of payment - £5000, £500, £20, free fertility treatment (for egg/sperm donation)?
  - Should some other incentive be offered – recognition in a letter, free/ cheaper fertility treatment if he needs it, a donation to charity – is it the money or where it goes?
  - Does it make a difference if the payment encourages or dissuades donation – i.e. is **there** a 'principle' to payment or is it just a means to an end?
- Dennis
  - Should Dennis' clinic be offering payment for sperm donation?
  - Is it appropriate? If so when – as a rule or only if it works to encourage donation (ends justifying means)?
- Rupali
  - Should Rupali's need for a donation weigh into this decision?

## Incentives and recognition 2 – Philip, Monica and Foluki

### FICTIONAL SCENARIO

- Philip is 32. A few years ago while waiting in his doctors surgery he saw a poster advertising organ donation. It said that if he registered to be a donor he would be prioritised for a transplant over those not on the register if he ever needed one
- Philip found this appealing and so signed up to be an organ donor
- Monica has liver disease. Her doctors say that without a transplant she is likely to die within two years. She was not an organ donor.
- Philip also has liver disease now, but it **is** at a less advanced stage than Monica's.
- Foluki is the liver specialist treating both Monica and Philip. A liver becomes available which would be suitable for both. The transplant team decide to give it Philip because he was on the organ donor register

# Incentives and recognition 2–

## Probes

- Overall what do you think about this scenario?
- Who should receive the liver? Who has the better claim on it and why?
- Philip
  - Does the fact Philip agreed to be a donor mean that he should receive priority treatment? Why?
  - Does his motive for becoming a donor matter i.e. to receive preferential treatment, rather than because he thinks it is the right thing to do make any difference?
- Monica
  - Is it fair that Monica is denied treatment for which she has the greater need? Why?
  - Does it matter why Monica did not sign up – apathy, religious belief, unaware of scheme etc?
- Foluki

Under the organ allocation rules in this fictional scenario the organ would go to Philip before Monica as he signed the organ donor register. Foluki is the doctor for both of them

- How would she feel?
- How would she feel about her patient being treated over another patient with lower need?

## Incentives and recognition 3 – Val and Barry, Adam and Nathan, and Jo

### TRUE-TO-LIFE SCENARIO

- Val donates her body to medical science because she wants to try to help people after she is gone. She dies of bone cancer
- Barry is a researcher conducting early stage research into a new bone cancer drug. He uses some of the cancer cells from Vals body in his research
- Several years later this drug has been developed to the point where it is ready for ‘first in human trials’ (i.e. on healthy people to test the safety of the drug)
- Adam volunteers for the trial and is paid £800 for two days of testing
- Nathan is the specialist who carries out the trials on Adam
- Jo has bone cancer. She is being treated with existing chemo and radio therapies. However her doctors have said the disease is fatal and will eventually kill her

# Incentives and recognition 3–

## Probes

- Overall what do you think about this scenario?
- What do you think of the incentives involved?
- Val
  - Should Val/Val’s family receive any payment/recognition for her donation? Probe:
    - Eg shares in any eventual profits from the cancer drug, funeral expenses, inclusion in a memorial, letter to the family
  - Does it matter that she does it without any incentive/recognition? Would incentives destroy the value she sees in donating?
- Adam
  - Is the payment to Adam fair?
  - Does his contribution differ from Val’s? How?
- Barry and Nathan
  - Both tasks are contributing to the development of the same drug (and potential monetary gain) – are they different?
  - Should they pay for any input from the public? What?
- Does Jo’s need for a drug make any difference in this scenario?

<p><b>After Death</b></p> <p><b>Red dot</b> = This incentive would make YOU more likely to donate</p> <p><b>Blue dot</b> = It would be acceptable to change the rules so this incentive was offered to everyone</p>	<p>A recognition of your contribution e.g. letter of thanks, certificate, inclusion in public memorial, becoming part of a 'donor community'</p>	<p>A donation to charity of your choice now</p>	<p>A benefit in kind e.g. funeral expenses paid when die, free health insurance for 5 years now, priority for an organ in future</p>	<p>Token cash payment now i.e. enough to buy yourself a small present</p>	<p>Substantial cash payment now i.e. that would make a significant difference to you personally</p>	<p>No incentive required</p>	<p>Other (Please specify)</p>
<p>Agree now to donate tissue after death for life saving treatment, e.g. skin to treat burns victim</p>							
<p>Agree now to donate whole organ after death for life-prolonging transplant, e.g. heart, kidney, liver</p>							
<p>Agree now to donate tissue after death for life enhancing treatment, e.g. cornea to restore sight</p>							
<p>Agree now to donate organ or tissue after death for a publicly-funded research project on the causes of cancer</p>							
<p>Agree now to donate organ or tissue for a pharmaceutical company research study on a new anti-cancer drug</p>							

<p><b>During life</b></p> <p><b>Red dot</b> = This incentive would make YOU more likely to donate</p> <p><b>Blue dot</b> = It would be acceptable to change the rules so this incentive was offered to everyone</p>	<p>A recognition of your contribution e.g. letter of thanks, certificate, becoming part of a 'donor community'</p>	<p>A donation to charity of your choice now</p>	<p>A benefit in kind e.g. free fertility treatment, free health insurance for 5 years, priority for an organ in future</p>	<p>Token cash payment now i.e. enough to buy yourself a small present</p>	<p>Substantial cash payment now i.e. that would make a significant difference to you personally</p>	<p>No incentive required</p>	<p>Other (Please specify)</p>
<p>Blood donation for life saving treatment eg during an emergency operation</p>							
<p>Live organ donation for life-prolonging transplant e.g. kidney or lobe of liver</p>							
<p>Egg or sperm donation for fertility treatment</p>							
<p>Donation of 'left over' material removed during an operation for a publicly-funded research project on the causes of cancer</p>							
<p>Donation of 'left over' material removed during an operation for a pharmaceutical company research study on a new anti-cancer drug</p>							
<p>Taking part in a clinical trial run by a pharmaceutical company to test the safety of a new anti-cancer drug</p>							

# Welcome and Introduction

Frances Chinemana

Opinion Leader

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# Ground rules for the day

- Mobiles off
  - Make time for everyone to contribute
  - Respect the opinions of others
  - No right or wrong answers
  - Take a break when you need one
  - Enjoy yourself!
-

# Who is in the room?

- Staff from Opinion Leader
    - Working with you on your tables to chair your discussion and take notes
  - Staff from the Nuffield Council on Bioethics
    - Observing table discussions
    - Observers have been given guidelines not to interrupt, interfere or in any way get in the way of table discussions
-

# Welcome and Introduction

Marilyn Strathern

Nuffield council on bioethics

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# Who are we?

Organisers:

**NUFFIELD  
COUNCIL ON  
BIOETHICS**



Financial support:

**wellcome**trust

Thank you to At Bristol for providing the venue

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# Table introductions and discussion

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# Types of donation presentation

Keith Rigg

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# Types of human bodily material that can be donated

## During life

- Blood
- Whole organs eg kidney
- Partial organs eg lobe of liver or lung
- Tissue eg bone marrow
- Sperm, eggs and embryos
- Whole body eg taking part in drug trials

## After death

- Whole organs eg kidney, heart, liver, lungs
- Tissue eg corneas (eyes), skin, bone, heart valve, tendons, stem cells
- Whole body eg for medical training

# Purposes of donation

<p><b>Life saving</b></p> <p>eg skin to treat serious burns</p>	<p><b>Life prolonging</b></p> <p>eg kidney transplant</p>
<p><b>Life enhancing</b></p> <p>eg corneal transplant to restore sight</p>	<p><b>Life creating</b></p> <p>eg egg/sperm donation</p>

# Or – for research

For example:

- Tissue left over from an operation used in a university's scientific research study
- A person volunteering to test the safety of a new medicine for a pharmaceutical company

# UK facts & figures

- 1.4 million registered blood donors
- 17 million people on the organ donor register
- Last year – 3700 organ transplants, from 2000 donors
- 1000 were living donors (eg kidney)
- 2000 babies born each year from donated eggs, sperm or embryos



# Table discussion

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# Feedback session

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Break



Please be back by 11.40



# Table discussion

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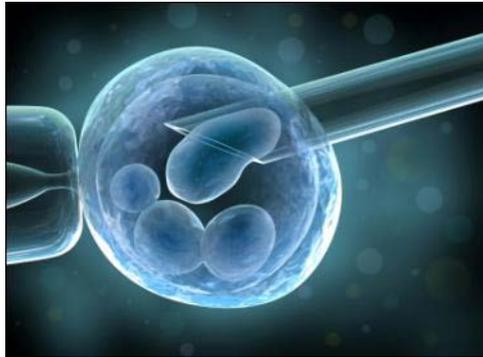
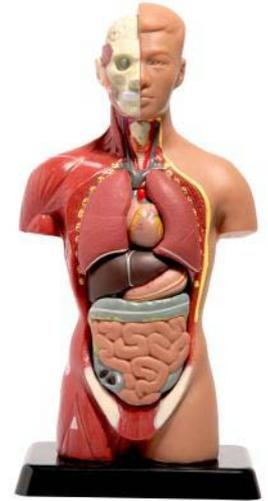
# Supply and demand

Naomi Pfeffer

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# Demand in UK

- 8000 people are waiting for an organ transplant
- 1000 people die each year while waiting (context: 500,000 die for other reasons)



- 1200 more egg donors and 500 more sperm donors are needed
- High demand for tissue for sports injuries, cosmetic surgery, hip replacements

- Supplies of blood constantly under pressure, but keeping up with demand
- Scientists have difficulty getting tissue for research



# Reasons why don't people donate

There are health risks involved

I don't want other people having my children

I'm squeamish

It's against my religion

I won't donate sperm unless I can remain anonymous

Not got round to it

I want an open coffin funeral so need my eyes intact

I haven't really thought about it

They might start taking my organs before I'm really dead

I don't like the idea of it

My heart is my soul

# Other reasons for the shortage

## Limits on supply:

- People have to die in a certain way to be able to donate their organs e.g. in hospital intensive care unit after brain injury = rare
- Number of people dying like this is falling (which is good!)
- Some types of donation depend on age e.g. eggs
- Bureaucracy in getting consent for living donation for research

## Increasing demand:

- People live longer but many more experience health problems associated with ageing (eg hip replacement operations)
- 'Lifestyle' factors are increasing demand for organs through, for example, alcoholism and obesity
- Advances in science and medicine mean more people can benefit from tissue transplants such as egg donation, repair of sports injuries, etc.

# Ways of meeting demand

## Already happening

- Increasing public awareness of need
- Improving transplant services in NHS
- 'Stranger' living organ donation

## Future options

- Providing more effective incentives for people to donate
- 'Opt out' system
- Health promotion to reduce need
- Allowing donation from more people (e.g. egg donation after death, organ donation from people who die outside hospital)

# Should we try to meet demand?

- Just because you want something (e.g. a new TV) should you get it?
- Would increasing supply just lead to ever increasing demand? E.g. more eggs = more women applying for fertility treatment
- Is it right to 'encourage' people to donate?
- Is all demand the same? Eg for cosmetic surgery, sports injury, tooth implants

# Table discussion

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Q and A

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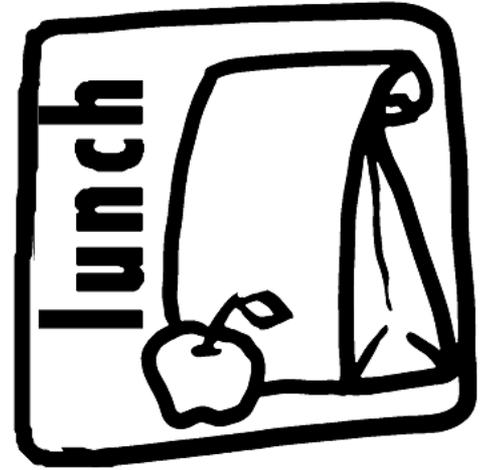
# Table discussion

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# Feedback session

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Lunch



Please be back by 1.15

# Table discussion

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# Consent and Control

Bobbie Farsides

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# Consent for donation during life

- Doctors & researchers must have consent from donor for removal & use of bodily material during life
- Children can give consent if mature enough
- ‘Left over’ tissue can be used for research without consent if approved by ethics committee and donor is anonymous

**No one can legally ‘own’ a human body**

# Donation after death

- You can give consent in advance for donation after death (= organ donor register)
- If not on register, your family will be asked to decide
- Families have no legal right to override decision, but doctors rarely go against family wishes
- About 60% of families in this situation consent to donation



# Controlling what happens to your donation

- All donors can decide if donation is used for treatment or research
- Living donors can specify who gets their donation e.g. a family member
- For donation after death, can only choose recipient in 'exceptional circumstances'
- Sperm and egg donors can put restrictions on donation, e.g. 'my sister' or 'a married couple'

# What other countries do

- Austria** Presume you consent to donation unless you have 'opted out'
- Spain** Same as above, but family views are taken into account
- US** Families must be asked about donation before turning off life support
- China** Reports of organs being taken from executed prisoners without consent

# Table discussion

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Q and A

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# Table discussion

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# Feedback session

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Break



Please be back by 2.45



# Table discussion

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# Recognition and incentives

Gillian Lockwood

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# Current law on incentives

- No direct payment allowed for any kind of donation (but may be reimbursed for 'expenses')
- Blood donors have award scheme, such as certificates or colour-coded donor cards
- Egg donors offered free or discounted fertility treatment in exchange for eggs
- Contrast: healthy people who take part in some drug trials are paid significant sums of money

# Future recognition and incentives?

- Letters of thanks
- Public memorial
- Creation of 'donor community'
- Donation to charity
- Priority for an organ in future
- Private healthcare insurance
- Funeral expenses
- Share of profits for discoveries following donation of tissue
- Cash payment



# What other countries do

- Israel** Priority for organ if previously signed donor register
- USA**
  - Pennsylvania:** \$300 towards funeral expenses
  - Wisconsin:** Living organ donors get income tax deduction up to \$10,000
- Singapore** Donor recipients can offer to pay expenses or provide limited health insurance to donors

# Possible pros and cons of more incentives

## Pros

- More donors?
- Save money in other areas of NHS eg dialysis?
- Raising money for charities?
- More research into disease?

## Cons

- Pushing people to take risks?
- Stepping over 'the line'?
- Disrespecting the human body/corpse?
- Undermining altruism?
- Making people feel guilty?

# Table discussion

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# Feedback session

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Summing up tables discussion

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# Thank you

Please complete your questionnaires

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# Workshop on human bodies in medicine and research

## End of day questionnaire

We hope you enjoyed the event today. Before you go we would like you to repeat some of the questions you answered at the start of the day to see how, of at all, your views have changed over the day. We would also like to ask you some general questions about the event today to see what you thought of it and how we might have made it better for you. Please be as honest as possible in your responses as this is our opportunity to fine out how we can run events like this better in the future.

**Q1. Sometimes the demand for bodily materials for use in medicine and research may be greater than the supply available through donation. How important do you think it is to take steps to increase the amount of donation to meet the demand for bodily materials? Who you say it is.....?**

PLEASE TICK ONE OF THE FOLLOWING

Not at all important	Not very important	Neither important nor unimportant	Somewhat important	Very important
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Any comments:**

**Freedom of Information Act 2000**

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**Q2. Who do you think should have control over what happens to donated material e.g. what it is used for, who it is given to etc.**

PLEASE TICK ONE OF THE FOLLOWING

The person who donated it	
The family of the person who donated it	
The doctor/researcher who receives the donation	
The government	

**Any comments:**

**Q3. Please indicate how much you agree or disagree with the following statements:**

	Strongly disagree	Disagree	Neither agree nor disagree	Disagree	Strongly agree	Don't know
I think people have a duty to donate their bodily material (eg blood, organs) to help others						
I think that people should receive some kind of recognition for donating their bodily material to help others, eg inclusion on a public memorial or a letter of thanks						

I think that that people should receive extra benefits for donating their bodily material to help others, eg priority for an organ if they needed one in future, or free fertility treatment						
I think people should be paid cash to donate their bodily material						

Any comments:

**Q4. Have any of your opinions changed throughout the day? If so, what was it that made you change your opinion?**

**Q5. Based on your experience, please indicate whether you Strongly Agree, Agree, Disagree, Strongly Disagree or Neither Agree or Disagree with each of the following statements (by placing a tick in the relevant box)**

PLEASE TICK ONE OF THE FOLLOWING

	Strongly disagree	Disagree	Neither agree nor disagree	Disagree	Strongly agree	Don't know
a. I enjoyed taking part in the event						
b. There was enough time to fully discuss the issues properly						
c. The event was well organised and structured						
d. The information that was given to me was fair and balanced						
e. The event was run in an unbiased way						
f. I think events like this are a good way of consulting people about policies						
g. Working with the mix of people at my table was useful for discussion						
h. I have learned a lot from today's event						

**Q6. How would you describe the event you have just taken part in?**

PLEASE TICK ALL THAT APPLY

a) Interesting		e) Boring	
b) Enjoyable		f) Confusing	
c) Easy		g) Informative	
d) Important		h) Hard work	

**Q7. Do you have any additional comments?**

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**Q8. The outcomes of today's workshop will be written up in a report. Would you like to receive a copy of the report?**

PLEASE TICK ONE OF THE FOLLOWING

Yes	
No	
Don't know	

**Q9. Would you like to receive future updates about how today's workshop influenced the work of the Nuffield Council on Bioethics on human bodies in medicine and research?**

PLEASE TICK ONE OF THE FOLLOWING

Yes	
No	
Don't know	

**IF YOU ANSWERD YES TO Q8 OR Q9, PLEASE FILL IN YOUR CONTACT DETAILS BELOW**

**Name:**

**Address:**

**Telephone:**

**Email:**

**Please hand this back to your table facilitator**