My Heart Belongs To You

Scenario 1: Life or death
(decision based on patient rights and choices)

- Sam is 15 years old and has been ill for most of his life. You are part of a team of doctors who have to make a recommendation about his care.

- Because Sam and his parents disagree about what should happen next, the hospital has gone to court to ask for a legal decision to be made about what action should be taken.

- Half the group will start from Sam's perspective while the other half will start from his parents' perspective.

- Spend the first **15 minutes** in your own group, read through the information on your cards and talk through your points about Sam and the reasons behind them.

- Then split into pairs and threes, find a pair/three from the other group and spend the second **15 minutes** Sam's perspective and his parents' perspective.

- Make your decision, choose a spokesperson and get ready to present your decision and the reasons for it to the whole group.

Medical background

Sam was born with a congenital heart disease, he had multiple heart abnormalities that surgeons tried to correct, but his lungs became damaged because of his heart problems. He was on the waiting list for a transplant and received a heart and lung transplant at the age of 5. He has spent most of his life in and out of hospital because of repeated episodes of heart failure, and is on oxygen at home to help him breathe.

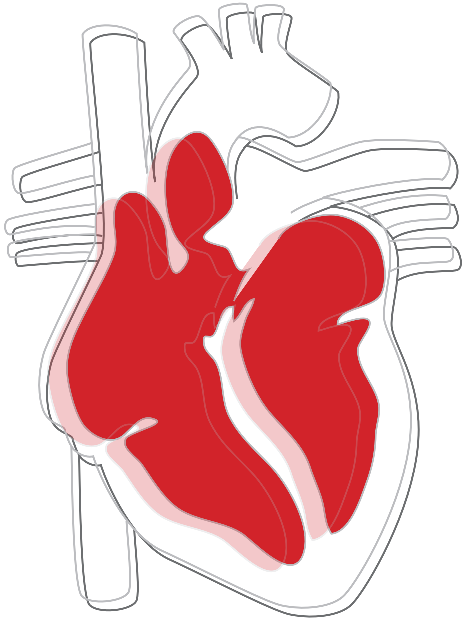
Because of the transplant, Sam is on drugs to prevent his immune system rejecting his new organs. The immunosuppressants make Sam vulnerable to infections. This means that he needs lots of tests in hospital: a range of pathologists are involved in his treatment, including tissue pathologists to look at biopsies of the heart muscles, and microbiologists to diagnose and treat any infections.

Sam developed leukaemia (blood cancer) when he was 12 as a result of his long term use of immunosuppressant drugs. Sam was in hospital even more for treatment, requiring multiple painful bone marrow biopsies, which he needed a specialist haematologist to diagnose and treat. Part of the treatment of his leukaemia involved reducing his immunosuppressive drugs, and this meant that Sam began to reject the heart and lung transplant he had when he was 5.

A multidisciplinary team is involved in Sam's care; pathologists, surgeons, physicians, specialist nurses, even play therapists and occupational therapists for young people. The team manage to get the leukaemia under control and he goes into remission, but Sam's heart is badly damaged because of the treatment, and he goes onto the waiting list for a second transplant when he's 15.

Sam’s story

I’ve been ill all my life. I was born ill and there’s not been a year when I’ve not been in hospital for one test, treatment or operation. I’m sick of it. I’ve had loads of biopsies (where the cut out a bit of your body for testing), countless operations and now they’ve put me on a waiting list for a second heart transplant! I don’t want it, I don’t want any of it anymore and all I want is to live what’s left of my life in a more normal way at home with my mum and dad. This has been no kind of a life so far, and since I’m going to die, I’d rather live what’s left of my life with some dignity, without any more painful operations. Keeping me alive has become my parents’ whole life, and I dread to think what another 10 years of this will do to them. But they seem so focused on wanting the next treatment that they’ve lost sight of what I want. This court case will decide whether I stay on the waiting list, because I’m only 15 I don’t have the right to decide my own treatment.



Discussion issues

- Who has the right to decide about these life or death decisions?

- Who has the ‘child’s’ best interests at heart; the doctors, the parents or the child? From a medical point of view, doctors have to act in a patient’s best interest. Can a ‘best interest’ be allowing the patient to die through their own choice, or are we aiding and abetting suicide? Should Sam be allowed to force a doctor into making that decision?

- How old do you have to be to make up your own mind about something that may have a negative impact on your health? (this is called competence irrationality i.e. refusing)

- Is it fair that Sam should be able to register for a second transplant after the first one was rejected? (especially if he develops another life threatening illness or this heart is also rejected)

- Should the law have the right to force a patient into having treatment against their wishes?

- Does Sam owe his parents anything-they sacrificed a lot for his sake?

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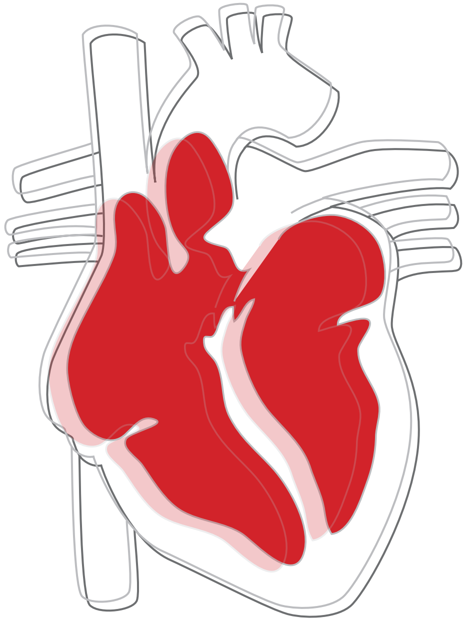
Sam's parent's story

We've focused our whole lives around trying to keep Sam alive and now he's saying he doesn't want the second heart transplant – we can't believe it! As Sam's mother I gave up my job, I had been running my own business but I resigned to look after my son, and my husband downsized so he didn't have to travel as much. We've never had a family holiday because of Sam's illness, and we decided not to have any more children even though we had wanted a large family, because of the time and energy we had to invest in Sam to make sure his health was managed as well as possible. We're just desperate for him to live! Of course we care that his life has been so hard, but we can't just let him die. We've taken the case to court because he's still so young, and he doesn't understand all the issues involved. If this second heart transplant can help him, we'd never forgive ourselves for letting him turn it down.



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- Does Sam owe his parents anything-they sacrificed a lot for his sake?

Scenario 2: Two patients, one liver: you decide

(Decision based on a one organ, two patient's scenario)

- Two people need a liver transplant but only one liver is available. You are on the panel of doctors including pathologists who have to decide which patient will receive the new liver.

- Split into two groups, one group will argue on behalf of the first patient and the other on behalf of the second patient.

- Spend the first **15 minutes** in your own group, read through the information on your cards and talk through your points about why your patient should get the liver and the reasons behind them.

- Then split into pairs and threes, find a pair/three from the other group and spend the second **15 minutes** discussing which of the two patients should get the liver transplant.

- Make your decision, choose a spokesperson and get ready to present your decision and the reasons for it to the whole group.

Patient 1

Medical background and treatment

Patient 1 is female and in her mid thirties and urgently requires a liver transplant because of advanced liver cirrhosis. The cirrhosis has led to blood clotting problems and as a result she needs blood transfusions. She is in and out of hospital receiving treatment for a series of bacterial infections as well as the transfusions, because bacterial infection can be a complication of cirrhosis.

Patient 1 is cared for by a range of different pathologists including a histopathologist to monitor the severity of the cirrhosis, a biochemist to check the chemical imbalances in her blood, a haematologist to assist with her blood transfusions, a microbiologist to help with her bacterial infections, as well as the medical and nursing care she receives on the hospital ward.

Social and personal context

The tests, treatments and staff required to help patient 1 are expensive and time-consuming. As well as tiring, painful and emotionally distressing (as she knows her life is at risk) being so ill is also difficult for her as she has to go into hospital for the transfusions, so has to organise childcare, but has no relatives to help her.

She is a white, single mum, living in South Wales with two young children (3 and 5 year old). The children's father and their new born baby brother died a few years earlier in a car accident (the father was on the organ donor list, as is this patient). Sadly, after the death of her husband and new baby, the patient, began drinking heavily. A year ago, with the support of her mother, who has since also died, she went into a recovery programme for alcoholics and managed to stop drinking. However, her liver is irreparably damaged and she needs a transplant. Since she's currently stable, has been off alcohol for well over a year and is engaging in treatment, she is eligible for a transplant. She is on the organ donor list as was her husband.

Discussion issues: Patient 1

- Should organ transplant go to the patient who will be easier to manage? There are more treatment options for the alcoholic cirrhosis than the viral cirrhosis, so does patient 1 need the new liver as badly as another patient?

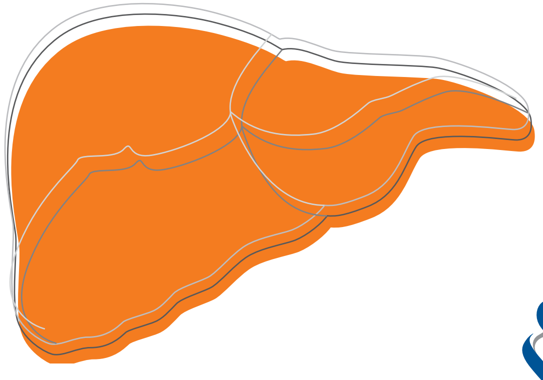
- Who will look after the two children if both their parents are dead? With no surviving relatives they will go into care – does this change how you think about saving their mother's life?

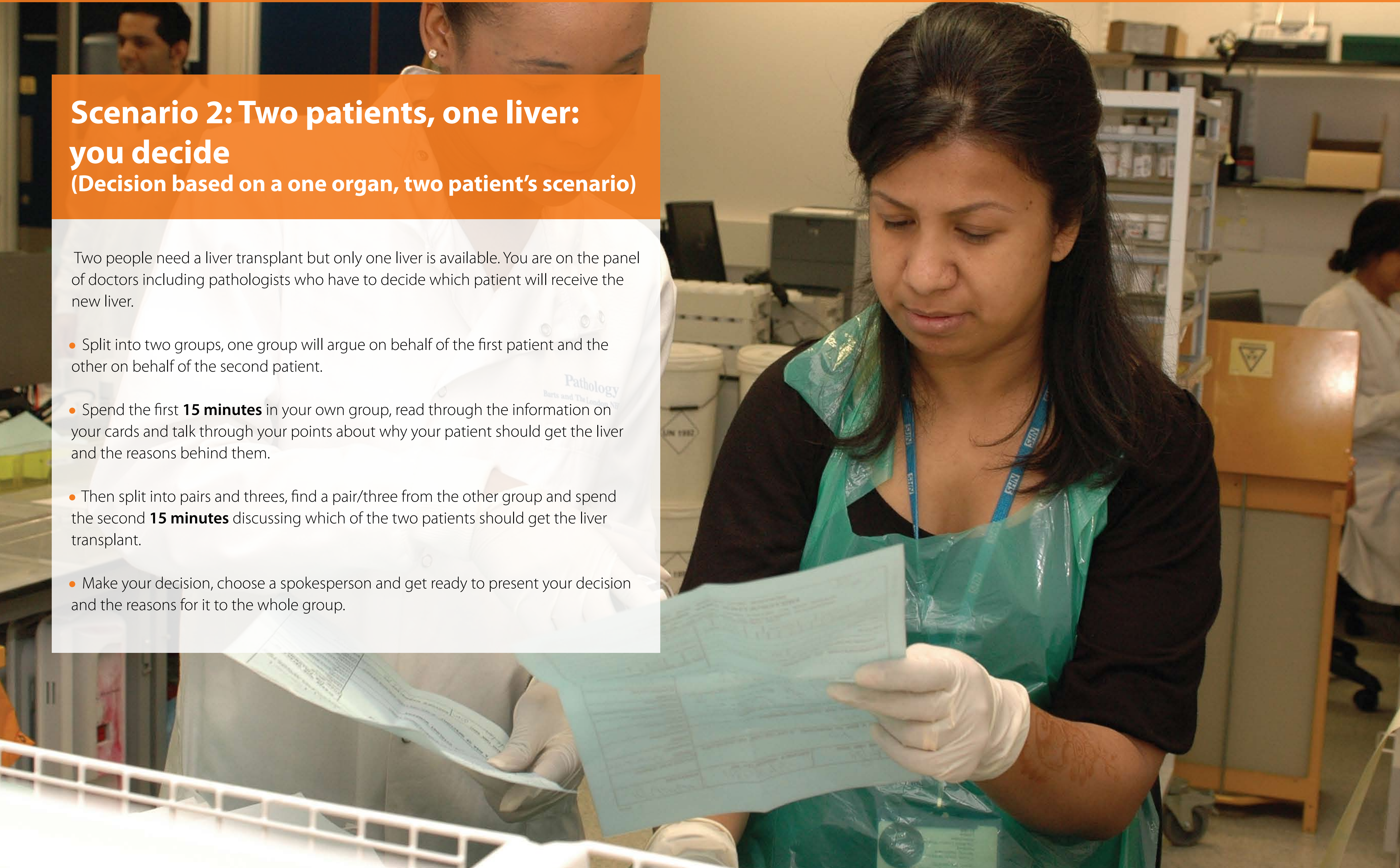
- Who is most valuable to our society? Should the transplant go to the person with greater clinical need, or the one who contributes most to society?

- Should you give a transplant to someone who has caused the organ damage through their own actions?

- She is on the donor list, should she be prioritised over other patients who are not on the organ donor list?

- What if the ethnicities of the patients were reversed – if patient A was from an Asian family (all on the organ donation list) and patient B was from a white family (none of whom are on the organ donation list), would this make a difference to who should get the one available liver?





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- Split into two groups, one group will argue on behalf of the first patient and the other on behalf of the second patient.
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- Then split into pairs and threes, find a pair/three from the other group and spend the second **15 minutes** discussing which of the two patients should get the liver transplant.
- Make your decision, choose a spokesperson and get ready to present your decision and the reasons for it to the whole group.

Patient 2

Medical background and treatment

Patient 2 requires a histopathologist to assess the degree of damage to his liver with a liver biopsy, and a biochemist to analyse his blood tests, as the damage to his liver will cause abnormal proteins and chemical imbalances in his blood stream. He also requires a virologist and an immunologist to check his antibodies and a haematologist to assist with his blood transfusions. Patient 2 has been on antiviral therapy. He takes an expensive drug called Interferon to stop the disease progressing. The Interferon causes neutropenia - a condition where patients have abnormally low white cell counts, reducing their ability to fight infection-so his blood needs to be regularly monitored by a haematologist, and he is also at risk of severe infections, for which he needs a microbiologist.

If he receives a transplant, and if the viral disease that caused the liver damage (Hepatitis C) starts attacking the new liver, the interferon treatment he had previously had can't be used. This is because it increases the risk of rejection. A post-transplant patient who has been transplanted for Hepatitis C liver disease requires a high level of medical care after the transplant.

Social and personal context

Patient 2 is an elderly Sikh, who became a UK resident after studying at Oxford University. He lives in London, has never married and has no dependants, but as a scientist is an active university lecturer and supervises PhD students. He has liver cirrhosis on the basis of long standing Hepatitis C that he acquired in his home country when he was having treatment for polio as a child.

The tests, treatments and staff required to help this patient are expensive and time consuming. In particular, the Interferon anti-viral therapy he needs to treat the hepatitis is very expensive. Being ill and spending a lot of time in hospital has meant he has had to reduce his teaching time at the university, but he has started living with his sister's family, who are looking after him. He is not on the donor list, neither is anyone in his family. Very few Asians are registered organ donors, and this means there might be a higher risk of his body rejecting a new liver, because it is unlikely to come from an Asian donor. He's eligible for a liver transplant.

Discussion issues: Patient 2

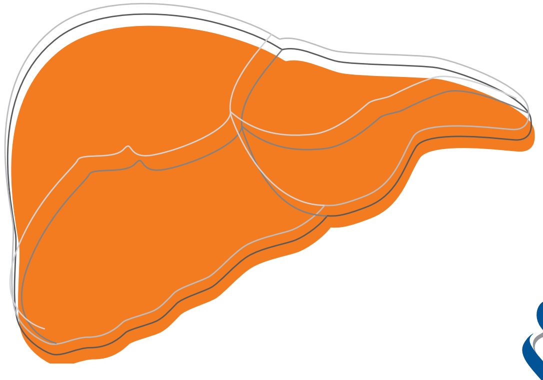
- Should organ transplant go to the patient who will be easier to manage? There are more treatment options for the alcoholic cirrhosis rather than the viral cirrhosis, so does patient 2 need the liver more than a patient whose liver damage was caused by alcohol?

- Does the medical profession have an increased duty of care to look after him because the damage to his liver resulted from adverse effects or complications od previous medical treatment?

- He is a world-renowned scientist who developed a new type of antibiotic and thus saved countless lives – does this change how you think about whether he should have the liver transplant? Is he more valuable because of his contribution to society?

- He is not on the donor list, if people on the list were given priority for the available organs, would the resulting low number of Asian organ recipients be an example of racism?

- What if the ethnicities of the patients were reversed – if patient A was from an Asian family (all on the organ donation list) and patient B was from a white family (none of whom are on the organ donation list), would this make a difference to who should get the one available liver?



My Heart Belongs To You

Scenario 3: Opt in/opt out?
(decisions about organ legislation)

- You (students) take on the role of Pathologists involved in making recommendations about new organ donation legislation. One half is trying to push a new pro-donation policy through and the other half is fighting against the new legislation.

- Split into two groups, one group will argue on behalf of the new legislation and the other against it.

- Spend the first **15 minutes** in your own group, read through the information on your cards and talk through your points about why the legislation should be passed and the reasons behind them.

- Then split into pairs and threes, find a pair/three from the other group and spend the second **15 minutes** discussing the legislation.

- Make your decision, choose a spokesperson and get ready to present your decision and the reasons for it to the whole group.

The current situation in the UK

In the UK we rely upon a voluntary system of organ donation. 7,985 people in the UK were waiting for an organ transplant in April this year (2009), most of them will never receive the transplant they need because there are not enough transplant donors, despite high levels of public interest and support for donation.

"Over 15 million people have registered with the organ donor register, but this represents only 25% of the population compared to the 65% or more that say they are prepared to donate organs after their death. This strongly suggests that the current system is inadequate and playing a part in this disparity".
P. 8. 2008. Department of Health.

In 2008 only 977 people received life saving transplants for heart, lung, liver, kidney, pancreas, or multiple transplants. Few donors are from minority ethnic backgrounds. Since transplants work better when donor and patient are similar, are people from minority ethnic backgrounds disadvantaged by the current system as a result? Is the voluntary system of organ donation in the UK putting people's lives at risk unnecessarily?

"I have not got a card. It never occurred to me. I would not use my day off to go and get a card." **(participant, London) P. 21. 2008. Department of Health.**

The proposed legislation

New legislation will automatically register everyone on the electoral role as an organ donor to tackle the chronic organ shortage in the UK. This policy aims to translate public support for transplants into actual donations by changing the voluntary nation of donation. Instead of relying on people signing up to donate organs, the new policy reverses the system and makes every citizen an organ donor. If you don't want to donate you would have to register you non-donor status.

Policies like this already exist in Belgium, Spain, Singapore and Austria, but some differences. In Austria organs can be taken from everyone who dies, unless the registered to opt-out. This is the case even if relatives object and the patient was known to object but never opted-out officially. In Spain and Belgium the families of dead people may prevent organs being taken for transplantation. In Spain doctors are required to ask patient's families, but in Belgium they are not, this is known as a 'hard opt out system'.

"I don't believe in a hard opt out system. People can change their minds right up to the moment they die, and they might have confided in a close family member."
(participant, London)p.12. 2008. Department of Health.

In Singapore not only are families not asked for their consent to donations, but those who opt-out of donor registration are de-prioritised for transplants against those on the register. However, in the UK people whose families will donate an organ or tissue for them are prioritised against other patients, so some argue the current UK system is also unfair.

"the [organ donation] Taskforce feels that moving to an opt out system at this time may deliver real benefits but carries a significant risk of making the current situation worse."
P.5. 2008. Department of Health.

What approach should the UK take to organ donation?

Discussion issues: Pro-new legislation

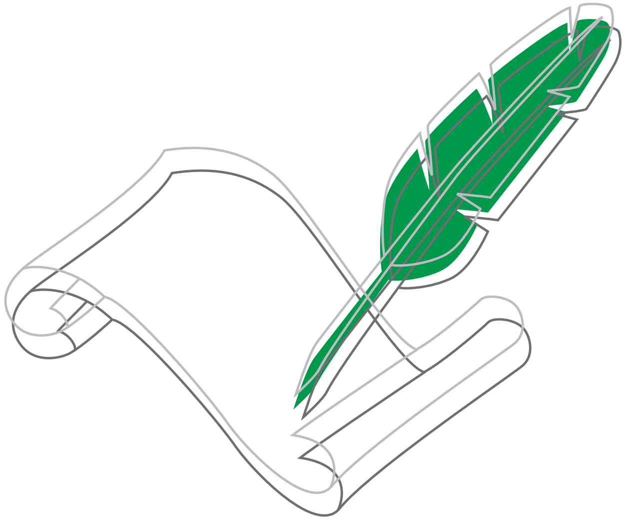
- *"Opt out or opt in is highly commendable – it says we take responsibility for our own actions – it says we can't all agree but we can make a decision."* (participant, Birmingham). P. 13. 2008. Department of Health.

- Is the system in the UK fair at the moment? It is voluntary, so relies upon good will and if you have a family member who is willing to donate an organ or tissues to you, you jump to the top of the transplant queue.

- How much consent is enough? Should family consent be obtained or is the patients name on the donor register (and the fact that that they didn't opt-out) enough authority for donation to go ahead?

- Taking organs from dead and dying people may violate certain religious and social attitudes, (e.g. respect for the dead, and what about the hope of a miracle cure at the last minute?), but these groups are in the minority, should the system for the whole country be biased by these beliefs?

- As a member of a society don't you have a duty to donate organs to help that society?



The Royal College of Pathologists
Pathology: the science behind the cure

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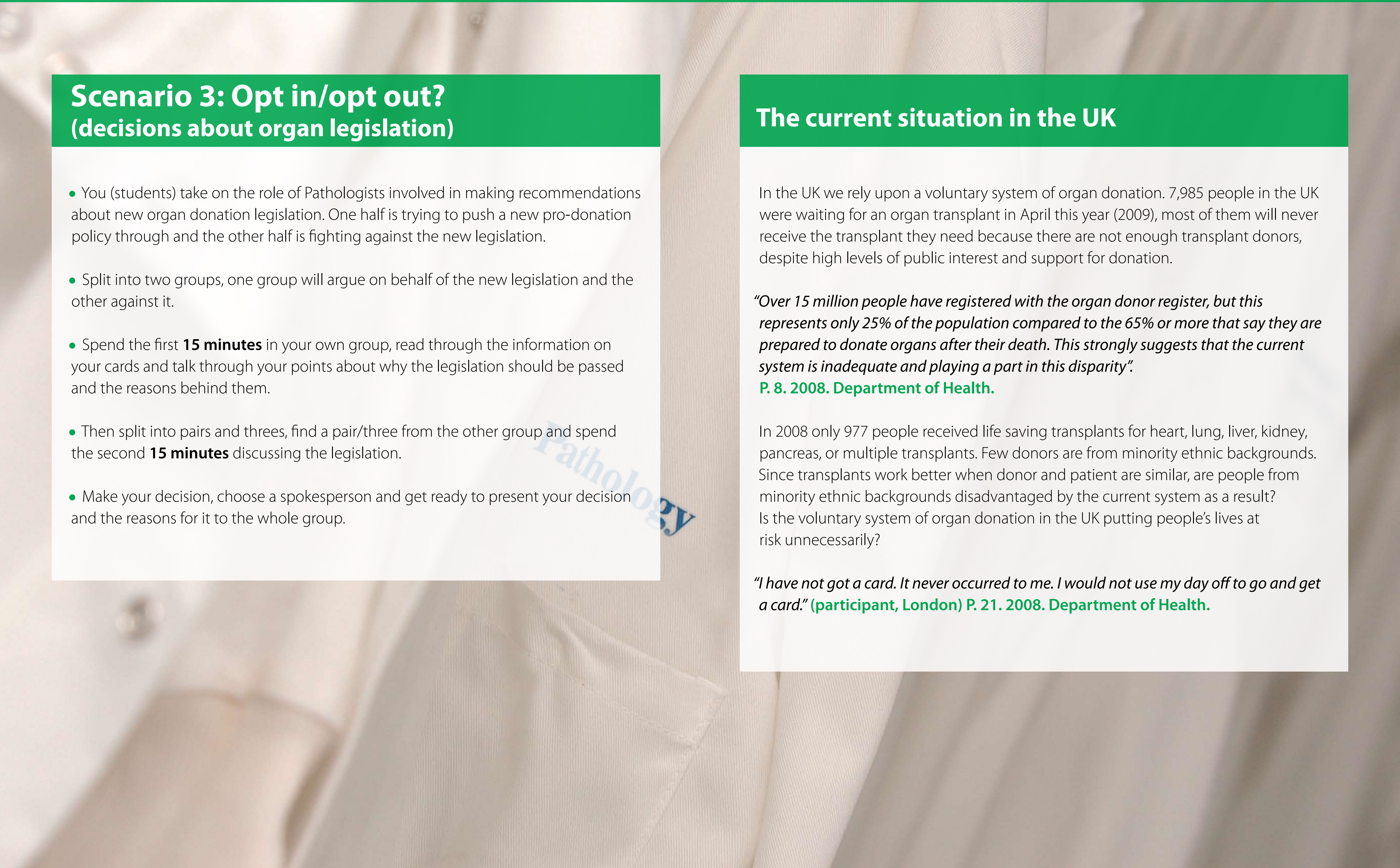

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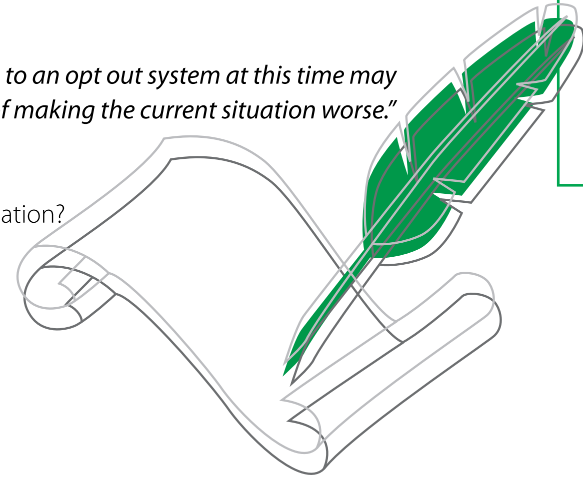

Discussion issues: Anti-new legislation

- *"There are always going to be people who won't fill in the form and won't make the decision – what happens then? I think it will complicate the system even further."* **(participant, Birmingham). P. 14. 2008. Department of Health.**

- Is the system in the UK fair at the moment? It is voluntary and if you have a family member who is willing to donate an organ or tissues to you, you jump to the top of the transplant queue.

- When is a patient dead? What is brain stem death? If the heart is still beating is the patient really dead and can you justify taking their organs (NB: organs for transplantation need to be collected while the person is brain dead but their heart is still beating)

- How much consent is enough? Should family consent be obtained or is the patients name on the donor register (and the fact that that they didn't opt-out) enough authority for donation to go ahead?

- Taking organs from dead and dying people may violate certain religious and social attitudes (e.g. respect for the dead, and what about the hope of a miracle cure at the last minute?) but these groups are in the minority, should the system for the whole country be biased by these beliefs?

- Should the government have a say in what you do with your bodies? (i.e. this is a very paternalistic approach to citizens and healthcare – is this appropriate)

Information from **www.uktransplant.org.uk** as of 25.6.09 and The potential impact of an opt out system for organ donation in the UK. Department of Health. 2008.

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