

Policy Maker

About your role

You are the leader of the group discussion. You have brought different stakeholders together to share their expertise and opinions. The goal of the group is to work together to make a decision that everyone can accept, even if it wasn't their first choice. Your group of experts includes:

- Healthcare Worker
- Health Economist
- Bioethicist
- Family Members of Certain Patient Groups, like children or patients who have alcohol use disorder

It is your responsibility to make sure that the process goes smoothly. It is also your responsibility to report your group's decision to the class and talk about how you made the decision.

Your group also includes a Potential Organ Donor. This person will not give input toward the decision but will observe the group and their process.

Scenario 1: Choosing a Policy

When choosing a policy, you want to make sure that everyone's voice is heard. Ideally, the policy you choose would do a good job of balancing the ethics principles of utility, justice, and respect for persons.

- **Utility:** Is the policy a good use of donated organs? Is the policy a good use of healthcare money? Does it maximize good outcomes? Does it minimize the potential harms or bad outcomes?
- **Justice:** Does everyone have a fair chance to receive a liver transplant? Is the policy based on evidence, or on opinion? Does stigma play a role?
- **Respect for Persons:** How will the policy be viewed by the public? Are all stakeholders satisfied with the policy?

Scenario 2: Applying your Policy

Remember the process and the conversation from Scenario 1. You want to make sure that this decision is aligned with the group's values that were discussed in Scenario 1.

- Is the group being consistent? Or are they changing their minds, or using different rationales?
- Are all stakeholders satisfied with the policy?
- How will this decision be viewed by the public?

Healthcare Worker

Background

The policy maker has asked you to join a group that will make decisions about organ allocation policy. The goal of the group is to work together to make a decision that everyone can accept, even if it wasn't their first choice. Other experts in your group are:

- Health Economist
- Bioethicist
- Family Members of Certain Types of Patients, like children with congenital liver disease, or patients who have alcohol use disorder

Your group also includes a Potential Organ Donor. This person will not give input toward the decision but will observe the group and their process.

About Your Role

You care for patients with liver disease every day. You are committed to providing the best care that you can for your patients in all stages– before transplant and after.

Your highest priority is to prevent deaths, to try to save the lives of as many dying patients as you can. There are many patients on the waitlist for a liver that are very sick and suffering a lot, who will die if they don't receive a transplant. This might include patients whose illness was caused by alcohol use.

Your second priority, after preventing patients from dying, is to reduce their suffering and improve their quality of life. You try to choose treatments that will make the biggest improvements to your patients' health and overall quality of life.

Scenario 1

Questions to Consider:

- Which one of these policies will save the most people from dying?
- Which one will result in the greatest improvements in health?
- Which one will reduce the most suffering?

Scenario 2

Questions to Consider:

- Who is most likely to die without a liver transplant?
- Who is suffering the most?
- Whose life will be most improved by receiving a transplant?

Health Economist

Background

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- Healthcare Worker
- Bioethicist
- Family Members of Certain Types of Patients, like children with congenital liver disease, or patients who have alcohol use disorder

Your group also includes a Potential Organ Donor. This person will not give input toward the decision but will observe the group and their process.

About Your Role

You are an economist, someone concerned with the finances of healthcare and organ allocation. You are a utilitarian and want to achieve the most cost-effective system for allocating livers.

You want each liver transplant to be the best use of the resource, with the greatest benefit to the individual and to society. You are interested in creating the healthiest people, so that they can live long lives contributing to the economy.

You want to minimize wasteful spending of healthcare dollars. You know that, as a society, we have limited money to spend on healthcare. Paying more money for one patient's treatment might mean there is less money for someone else.

Scenario 1

Questions to Consider:

- Which policy results in the largest benefit to the individual and/or to society?
- Which policy results in patients living longer, more productive lives?
- Which policy reduces wasted resources?

Scenario 2

Questions to Consider:

- Which patient will benefit the most?
- Which choice will result in the best outcome for the economy?
- Which patients' healthcare will cost the least?

Bioethicist

Background

The policy maker has asked you to join a group that will make decisions about organ allocation policy. The goal of the group is to work together to make a decision that everyone can accept, even if it wasn't their first choice. Other experts in your group are:

- Healthcare Worker
- Health Economist
- Family Members of Certain Types of Patients, like children with congenital liver disease, or patients who have alcohol use disorder

Your group also includes a Potential Organ Donor. This person will not give input toward the decision but will observe the group and their process.

About Your Role

The Organ Procurement & Transplant Network defines justice as “fairness in the pattern of distribution of the benefits and burdens of an organ procurement and allocation program.” This means that everyone has a fair chance to get on the waiting list and a fair chance to receive an organ that becomes available. It also means that the benefits of the policy are distributed fairly over the entire US population, not favoring one group over another or making one group unfairly suffer more than others.

You are a bioethicist, researcher, and advocate for justice in the healthcare system, and in liver allocation specifically.

You know that societal factors like income, race, age, and gender can have an unfair impact on someone's healthcare experience. For example, Black Americans are often sicker than white Americans when they are initially put on the waitlist for an organ. Or, some people cannot afford the treatments they need to stay healthy. You want everyone to have a fair chance to get the treatment they need.

You worry that stigma and discrimination might play a role in policy making. You believe healthcare policies should be based on evidence, not on assumptions.

You also believe it is important to prioritize helping patients who are the worst off. Patients who will die without a transplant, or who are suffering a lot from their disease, should be helped first.

Scenario 1

Questions to Consider:

- What factors might be playing a role that make these policies unfair?
- Which one is the most equitable?

Scenario 2

Questions to Consider:

- Which patient might face discrimination or stigma?
- Which patient is worst off?

Family Member of a Child with Liver Disease

Background

The policy maker has asked you to join a group that will make decisions about organ allocation policy. The goal of the group is to work together to make a decision that everyone can accept, even if it wasn't their first choice. Other experts in your group are:

- Healthcare Worker
- Health Economist
- Bioethicist
- Family Members of Certain Types of Patients

Your group also includes a Potential Organ Donor. This person will not give input toward the decision, but will observe the group and their process.

About Your Role

You are the parent of a child who was born with a rare liver disease. There are some medicines that these children can take to manage the disease for a few years, but they will need a liver transplant by the time they are 10 years old. Once they've had a transplant, the disease is cured and the child can live a long, healthy life.

This disease is not a result of the child's behavior or any choices you or your child have made- it's no one's fault.

You want to see your child live a long, normal life. You want to see them graduate from school, become an adult, and achieve all of their goals.

Scenario 1 & Scenario 2

Questions to Consider:

- How might your child fare under each of these policies? Will they benefit? Will they be harmed?

Family Member of a Patient with Liver Disease Due to Alcohol Use

Background

The policy maker has asked you to join a group that will make decisions about organ allocation policy. The goal of the group is to work together to make a decision that everyone can accept, even if it wasn't their first choice. Other experts in your group are:

- Healthcare Worker
- Health Economist
- Bioethicist
- Family Members of Certain Types of Patients

Your group also includes a Potential Organ Donor. This person will not give input toward the decision but will observe the group and their process.

About Your Role

You are a relative of someone who has experienced liver disease due to alcohol use. These patients are very sick, suffering a lot, and are very likely to die without a transplant.

You do not want your relative to suffer or die. You understand that this was the result of their behavior but know that addiction is a difficult disease to fight. You are hopeful that, if given the chance, your relative will stay sober and live a healthy life after receiving a transplant.

Scenario 1 & Scenario 2

Questions to Consider:

- How might your family member fare under each of these policies? Will they benefit? Will they be harmed?

Potential Organ Donor

Background

The policy maker has brought together a group of experts that will make decisions about organ allocation policy. The goal of the group is to work together to make a decision that everyone can accept, even if it wasn't their first choice. The group includes:

- Policy Maker
- Healthcare Worker
- Health Economist
- Bioethicist
- Family Members of Certain Types of Patients, like children with congenital liver disease, or patients who have alcohol use disorder

About Your Role

You represent a member of the general public, who will decide whether or not to register to be an organ donor. Registering to be an organ donor means that you are giving permission for your organs to be allocated to people who need them after you die. However, even if you sign up, there is only a very small chance (less than 1%) that your organs will actually be donated.

During this exercise, you will not give your input to the group when they are making decisions. However, you will observe the group, their process, and their choices. Consider the questions written on your worksheet, and take note of how things are going. At the end of Scenario 1 and Scenario 2, please share your reflections with the class.

Is the conversation going well? Is everyone's view being considered equally? Does everyone have a chance to speak and be heard?

Do you trust the members of the group? Is this the right group of people to make this decision? Who is missing? Who would you add to the group?

Do you agree or disagree with the decisions they made? Why? How do the decisions make you feel? What is fair or unfair about the choices they made?

Was there any aspect that the group didn't think of? What were they missing?

Was the group consistent? Did they act according to their own values?

Would you volunteer to become an organ donor in the system your group chose? Why or why not?

Scenario 1

Your group must choose the national liver **allocation** policy. Consider the strengths and weaknesses of each option, share your opinions based on your role, and work together to make a choice. Keep in mind ethical principles like **utility**, **justice**, and **respect**.

Choose one of the following policies:

- A. **Lottery system**: everyone on the list has an equal chance to receive a matched liver, regardless of other factors
- B. **Sickest first**: the more likely you are to die without the transplant, the higher you are on the list
 - This would prioritize older, sicker patients
- C. **Maximum life-years saved**: you are higher on the list if you are more likely to live many years after the transplant
 - This would prioritize younger, healthier patients

Scenario 2

Apply the policy you chose in Scenario 1. One liver has become available, and three patients need a transplant. Using your policy, which of these patients would receive this liver?

- A. A 70 year-old retired person
- B. A 35 year-old person whose liver disease was caused by alcohol use
- C. A 2 year-old child