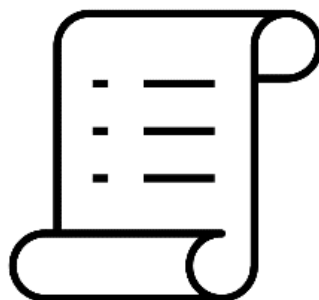


## Unit 2: History of Scientific Research with People and Rules



## Topic 2.1: History of Research with People



### Main Ideas

- **Good things can happen** when we do research.

The good things that can happen are called **benefits**.



- Research benefits can be for the person in the research study or for other people in the future.

- **Bad things can happen to people in research.**

The bad things that can happen are called **harms** or **risks**.

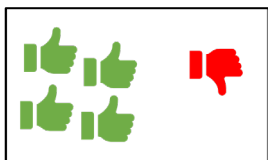


- Examples include hurting someone's body or feeling sad.

- **Research ethics** are about **making sure people are treated well** and that their **rights are respected** when they are in research.



- **Research ethics** are also about making sure **more good things happen than bad things** when we do research.





## Discussion Questions



1. When you **think about research**, what **pictures** or **words** do you think about? What **feelings** do you have?



## Discussion Questions



2. What do you think would be a **good experience** with research?

3. What do you think would be a **bad experience** with research?



## Discussion Questions

4. How do you think **good experiences** with **research studies** in the past might **make people feel about** being in research studies now?

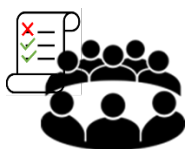


5. **Why** is it **important** to have **rules** for **research** with people?

## Topic 2.2.1: Rules for Scientific Research with People



### Main Ideas



- **Institutional Review Boards (IRB)** are groups of people who **make sure** researchers **protect people's rights and well-being**.

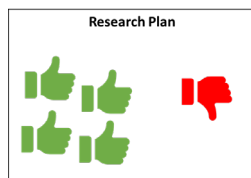
- The **Belmont principles** are the **values** that help us think about **how to treat people** when they are in research. They are:



- **Respect for persons** is about **believing** that **everyone can make decisions** with or without support. Respect for persons also means **taking extra care of people** who have a hard time making decisions.



- **Justice** is making sure **all types of people can be in research** and that everyone shares the good and bad things that can happen in research.



- **Beneficence** is about making research have **as many good outcomes** as possible and **keeping people as safe** as possible.



## Putting it into Action: Disability Rights and Research Rules



Talk with your team about how some of the **main values** in **research** and **disability rights** are **similar** and **different**.



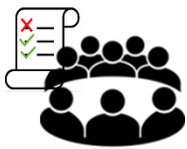
You may think of other disability rights—you can talk about those too.

Disability Rights	Research Rules (Belmont Principles)
<ul style="list-style-type: none"> <li>• Assuming people can do things and make choices               <ul style="list-style-type: none"> <li>○ This includes making choices that might not always work out or might be risky. This is sometimes called dignity of risk.</li> </ul> </li> <li>• Having the <b>same opportunities</b> as everyone else to do things</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Respect for persons</b></li> <li>• <b>Justice</b></li> <li>• <b>Beneficence</b></li> </ul>

## Topic 2.2.2: Institutional Review Boards



### Main Ideas



- 
- **Institutional Review Boards (IRB)** are groups of people who **make sure** researchers **protect people's rights** and **well-being**.
-





## Discussion Questions



### 1. **What does the IRB do?**

- **Why is what the IRB does important?**

## Topic 2.3: Vulnerability



## Main Ideas



- 
- It is important to be **extra careful with people** who are **vulnerable**. People who are **vulnerable** may **have a hard time making a decision** or need **help understanding and making decisions**. People who are vulnerable **may get hurt** by research more easily than other people.
-



## Discussion Questions



1. What **helps** you **understand** and **make decisions**?



## Discussion Questions



2. **How can you help people who have a hard time making their own decisions (“vulnerable”) make a choice about being in research?**

- How can we help people not feel pressured to make a decision?



3. **When we include people who may be vulnerable, what can we do to include them safely?**