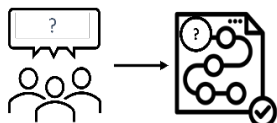## Topic 5.3: Wrap Up

Main Ideas

- **Scientific research** is **asking** a **question** and using a **step-by-step process** to **collect information** to answer the question.
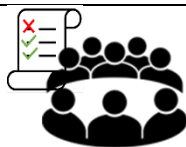
- In **community-engaged research,** community research partners **share** their **experiences** and **knowledge** to help make research questions that **matter** to **people with disabilities,** and do research that is **accessible** and **respectful**.

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

- Research ethics can **help** make sure **bad things** don't happen when people are in research.

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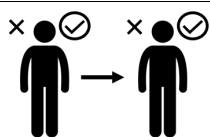
Main ideas

- **Eligibility criteria** are the **characteristics** and **experiences** that people **need** to **be in a** research **study**.

- **Only people** who have **all the characteristics** on the list **can be in the** research **study**. This list is different for every study.

- Consent must be:
    - **Informed:** people have all the information they need about the study.
    - **Voluntary:** people making their own choice without anyone pressuring them.
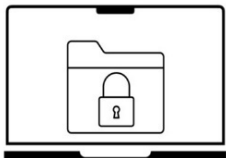   - **Ongoing:** people can say no at any time during the study.

- We often get **assent** from people when they have a **legally authorized representative (LAR). Assent** is when someone with a LAR **says** or **shows** with their body that they **want to be in** the **research** study

Main ideas

- We work together with our team to have **safeguards**. **Safeguards** are the things we do or use to **keep people safe** in research.

- Keeping **information private** and **confidential** is really important in research.

- We keep **information privat**e and **confidential before**, **during**, and **after** the **research** study.

- Mandatory reporting means if researchers learn that a research participant is being hurt or abused, they have to share the information with authorities (people who can stop other people from being hurt). Researchers also have to share information if they find out a research participant is hurting or abusing someone else.

	• **Your safety** as a community researcher is **important**. • Your team can **plan for what you will do** if a **community research partner is hurt doing research.**
	• **Authors** are the people who **share about** a **research** study. • If you are part of a research team, you m_{ay} **have the right to be an author**.
	• It is important to **reflect**, or **think about** what **you do** as a researcher. If we think together about what we do we can help keep participants **safe** and **respect** their **rights**.