How to Make a *Question* Become *Research*:

Everyone can do it!

Research reported in this presentation was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (#2539-UKY).

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Learning Objectives for this Overview

By the end of this session you will be able to:

1. Understand what research is.
2. Have a beginning understanding of the research process and why it is important.
3. Understand **Patient Centered Outcomes Research (PCOR).**
4. Understand how research can help you make the best decisions.

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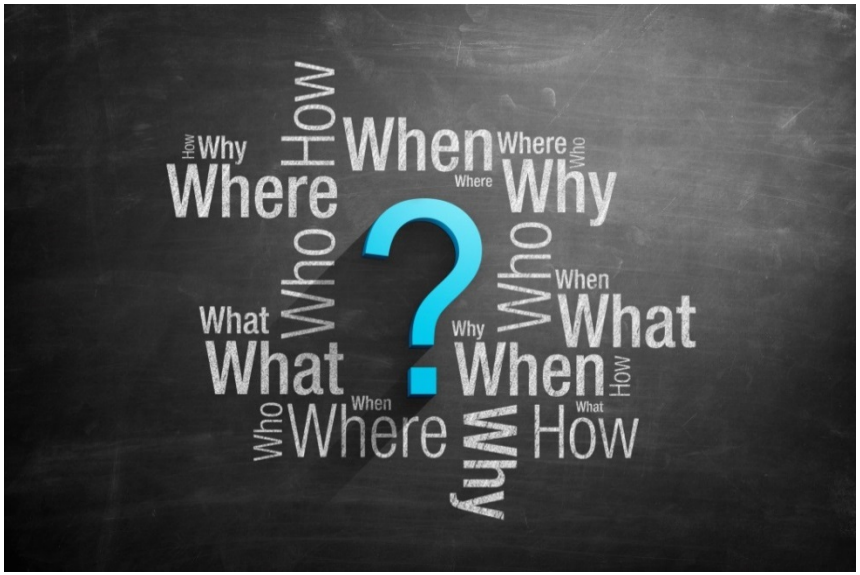
What is Research?

The word "**research**" is used to describe:

- A search for information



OR

- A detailed study of a subject, to discover (new) information or reach a (new) understanding.

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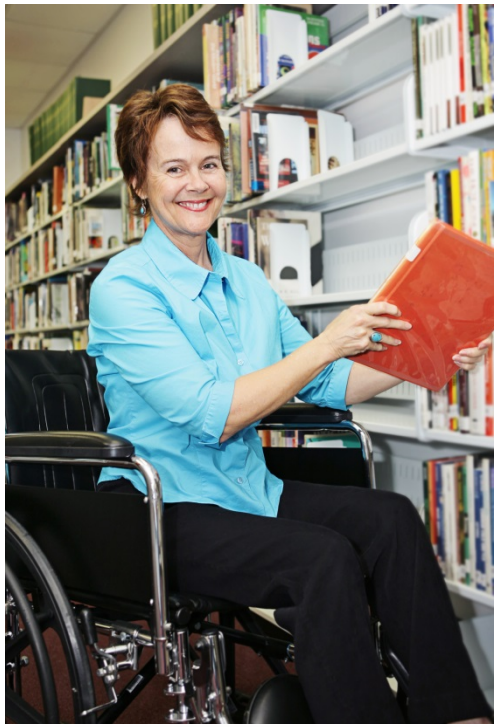
What is Research?

- This search for information can be as different as asking:

  - What is the best price for a new car?
  - What is the best way to make a library accessible for people in wheelchairs?
  - What is the best treatment for a particular disease?



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What is Research?

- At its core, research is just asking a question or a series of questions about a topic that is important to you.

- Everyone is capable of asking a question; therefore, everyone has the ability to be involved with research.

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Why is Research Important?

1. It allows us to answer questions about topics such as:
   - How to improve health (treatments)
   - The best way to perform a task
   - How the world around us works.

2. Also helps us determine what does ***not*** work

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The Research Process

Step 1: Identify the Research Question

A) Select a topic area.

- Stimulated by patient need, your passion, your experience

B) Conduct a thorough literature search.

- Online or in the library
- The literature review helps form the question
- It lets you know what information already exists

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The Research Process – Step 1, continued

C) Critically consider the literature you have read.

- Is it reliable? This is very important. Just because it is in print (or on the internet) doesn't make it correct.

D) Determine what is missing from the literature; what information is still unknown?

E) Develop the question you would like to ask or test.

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The Research Process

Step 2: Design the study –

How will you ask your question?

A) <u>Quantitative</u> <u>type research:</u>

- "**What** is happening?"
- Gather: measurements (numbers), surveys, questionnaires

Example: Measure A1c blood levels for people with diabetes who are trying a new drug.

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The Research Process

Step 2, continued: Design the study –

B) <u>Qualitative</u> <u>type research</u>.

- **"Why** is it happening?"
- Gather information: Interviews, focus groups
- *Example*: Discuss why people with diabetes are not taking a new medication even though it helps their illness.

C) <u>Mixed Methods</u>: includes **both**

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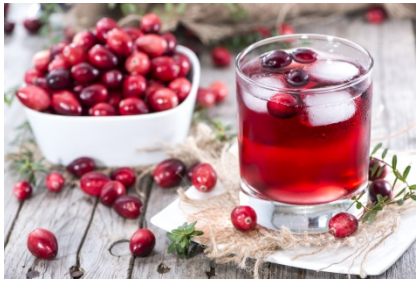
Examples: KARRN Research Questions

- What do people with spinal cord injury (SCI) who live in rural Kentucky need to improve their quality of life?

Examples:

- What are the issues people who use wheelchairs need to think about when traveling?
- What are the most effective methods to transition from the hospital back to the community?
- If cranberries help prevent urinary tract infections, is it better to eat them, drink cranberry juice, or take pills?



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The Research Process

Step 3: Develop the Methods (the nuts and bolts) – **How** will you ask/test your question?

- Who will do what?
- Are you working with people, cells, animals, etc.?
  - A whole population or just a small group?
- Sample Size
  - How many people do you need in your study?
- What type of measurements will you use?
  - Survey, interview, blood pressure, strength, etc.

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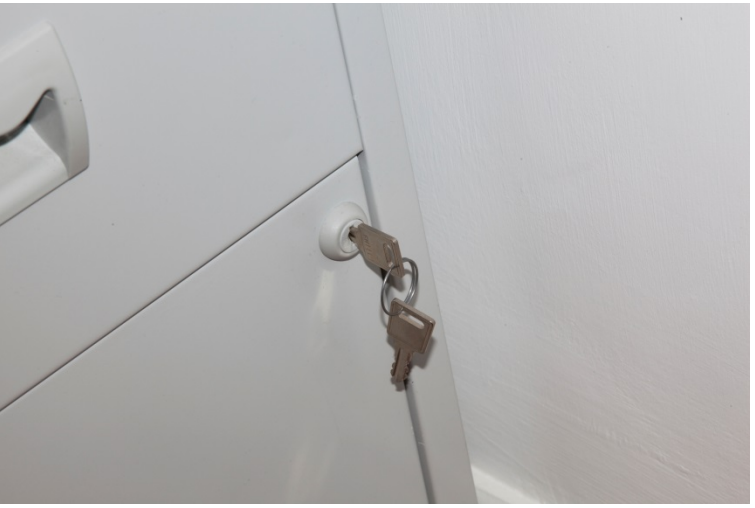
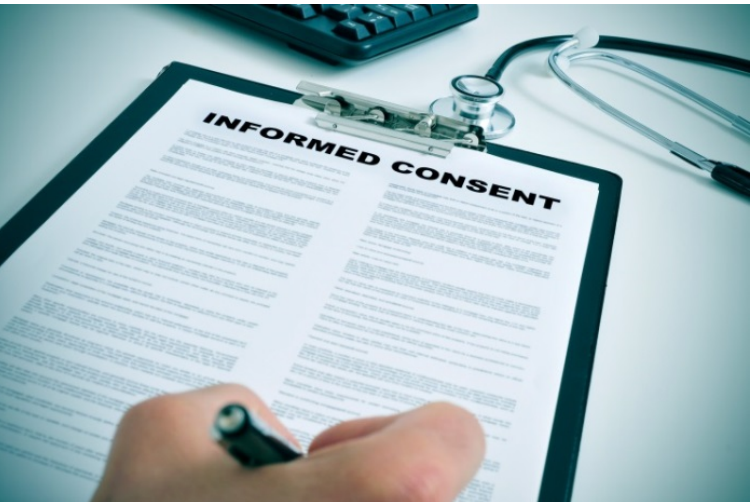
The Research Process

Step 4: Develop the Methods - Get Approval





- If you are working with people, an Institutional Review Board will need to approve the research to make sure the welfare of the subjects is taken care of, protecting them from harm and keeping their information private.
  - Forms must be approved to explain the benefits and risks of the research and obtain signatures for consent to participate.

The Research Process

Step 5: Data Analysis –
What do your results mean?

- Descriptive analysis (summaries, averages, etc.)
- Statistical analysis (more detailed “number crunching to find patterns and trends)
- Sometimes researchers can get help with analysis from experts
- Interview (narrative) analysis

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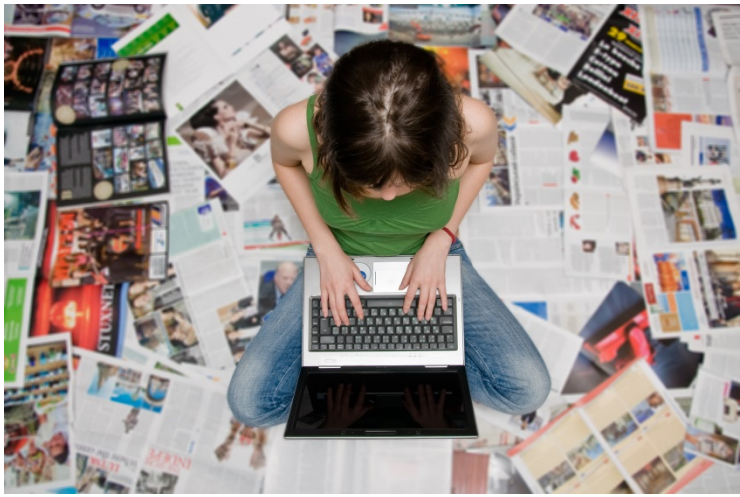
The Research Process

Step 6: Communication - How will you tell others what you have found out?

- Presentations (local, state, national, international)
- Publications
- On-line posting
- Newsletters
- Handouts/brochures
- In-service for your facility



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The Research Process

Step 7: Develop new **resources** based on the information discovered.

Examples:

- Develop registry of persons with SCI to follow them across different healthcare settings
- Develop peer-mentoring program for patients and for caregivers
- Training for health care providers (annual continuing education)

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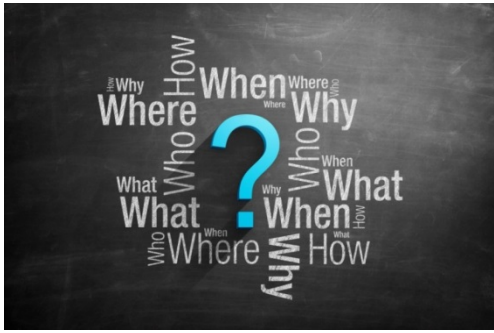
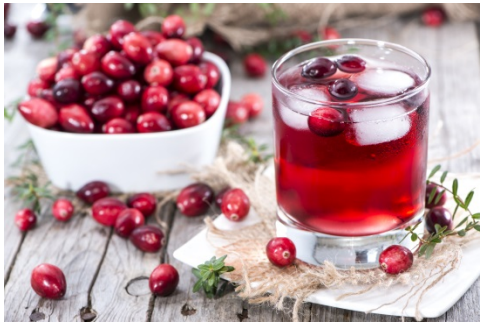
Step 8: Develop new **questions** based on the information discovered.



Examples:

- Is there a higher frequency of secondary complications in persons with SCI depending on where in Kentucky they live?
- What is the best method for developing a peer-mentoring program in rural communities?
- How much cranberry juice do I need to drink daily?



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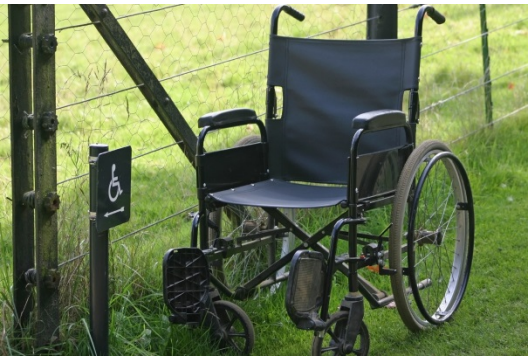
Qualitative Research Example: What do people with disabilities living in rural Kentucky need to improve their quality of life?

- Analyze interviews
- Identify common themes:
  - Wheelchair accessibility (e.g. state parks, restaurants, doctor's offices)
  - Activity levels after acute rehabilitation
  - Support from others with similar experiences
  - Health care providers who understand how to care for individuals with SCI, stroke, brain injury



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Quantitative Research Example: What do people with disabilities living in rural Kentucky need to improve their quality of life?

- How to manage diabetes
- Collecting A1c blood level scores from people who are trying a new diabetes drug

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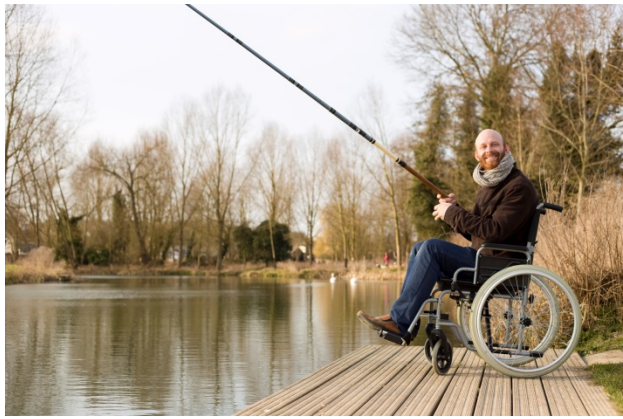
What is Patient Centered Outcomes Research?

- This type of research answers patient-centered questions. *Examples*:
  - "Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?"
  - "What are my options, and what are the potential benefits and harms of those options?"
  - "What can I do to improve the outcomes that are **most important to me**?"
  - "How can clinicians and care delivery systems help me make the best decisions about my health and health care?"



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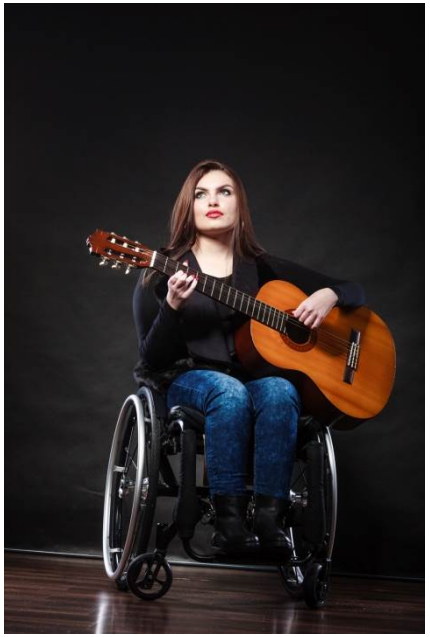
What is Patient Centered Outcomes Research?

- To conduct PCOR type research, the patient and caregivers (stakeholders) need to be involved in the research
  - What is important to you? (Question)
  - What would make something work or not work for you? (Intervention)
  - How do we get people to take part in the research that represents you and your needs? (Recruitment)
  - How do we get the research findings out to the people who can be helped (Dissemination)



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How does Patient Centered Outcomes Research work?

- **Patient Centered Outcomes Research** (PCOR) helps people and their caregivers make **informed** health care **decisions** and allows their **voices to be heard** in assessing health care options

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...In other words,

- People and caregivers **help determine** what needs to be researched and how it is researched

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Getting Involved in Research

- So how does someone get involved in research?
- How can a person help with a research project?
- How would I know what to do?

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How to get involved: Levels of Involvement in Research

- Planning a study:
  - Help us develop research questions and outcomes
  - Help define who the study participants should be
  - Design the study so it will actually work with the people we are going to recruit

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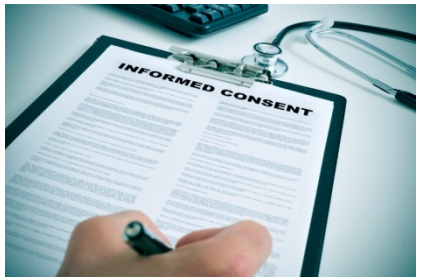
Levels of Involvement in Research

- Conducting the study:
  - Draft or revise study materials and procedures
  - Recruit participants
  - Data collection
  - Data analysis
  - Helping evaluate patient engagement to be sure they are being heard – **hold us accountable**



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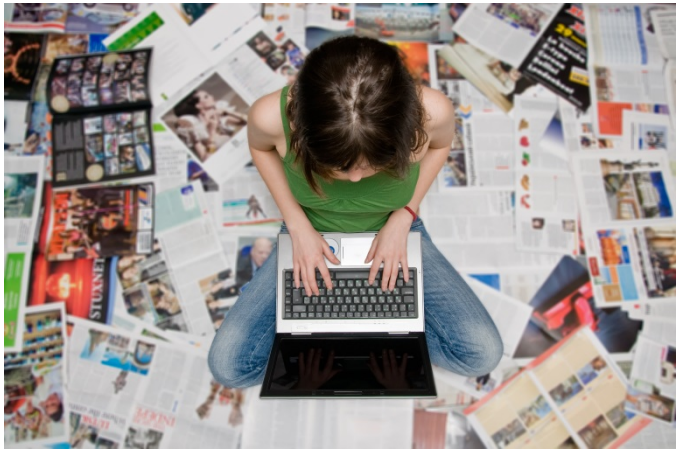
Levels of Involvement in Research



- Sharing Study Results:
  - Figure out who to share the study results with
  - Help to decide which ways to share study results
  - Present results to a variety of audiences
  - Help write up papers for publication

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Levels of Involvement in Research

- One-time volunteer experience
- Short-term partnership for a single project
- Long-term partnership

So you can be as involved as you want in research!

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- With grateful appreciation to our community partners for all of their constructive input.
- *The project was partially funded by a grant from the National Center on Minority Health and Health Disparities (1RC4MD005760-01)*

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