NYU Langone Health

# PARTICIPATION IN CLINICAL RESEARCH

From idea generation to publication...
Learn more about how research participants play a role in all various phases of human research.

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# RESEARCH TIMELINE

Select the bubble of your choice to get started

# UNDERSTANDING CLINCIAL RESEARCH

Medical research is the process of developing a plan to answer a research question about a disease or disorder.

Understanding what it entails and how it differs from your standard medical care is very important.

**Click the links to learn more about medical research and more >>>**

What is medical research?

Research vs. medical care?

Research with medical records?

Participating in social behavioral health research

**All links provided by U.S. Department of Health and Human Services - Office of Human Research Subject Protections*

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# IDEA GENERATION

A researcher may identify a knowledge gap regarding a disease or disorder. They may formulate a few ideas regarding ways in which it can be treated or prevented.

Idea generation sets the groundwork for hypothesis development and research planning.

Researchers often collaborate with community-based organizations that serve marginalized communities to identify research priorities.

# LITERATURE REVIEW

Members from community based organizations assist researchers in discovery and review of existing information regarding the disease or disorder.

community member contribute by...

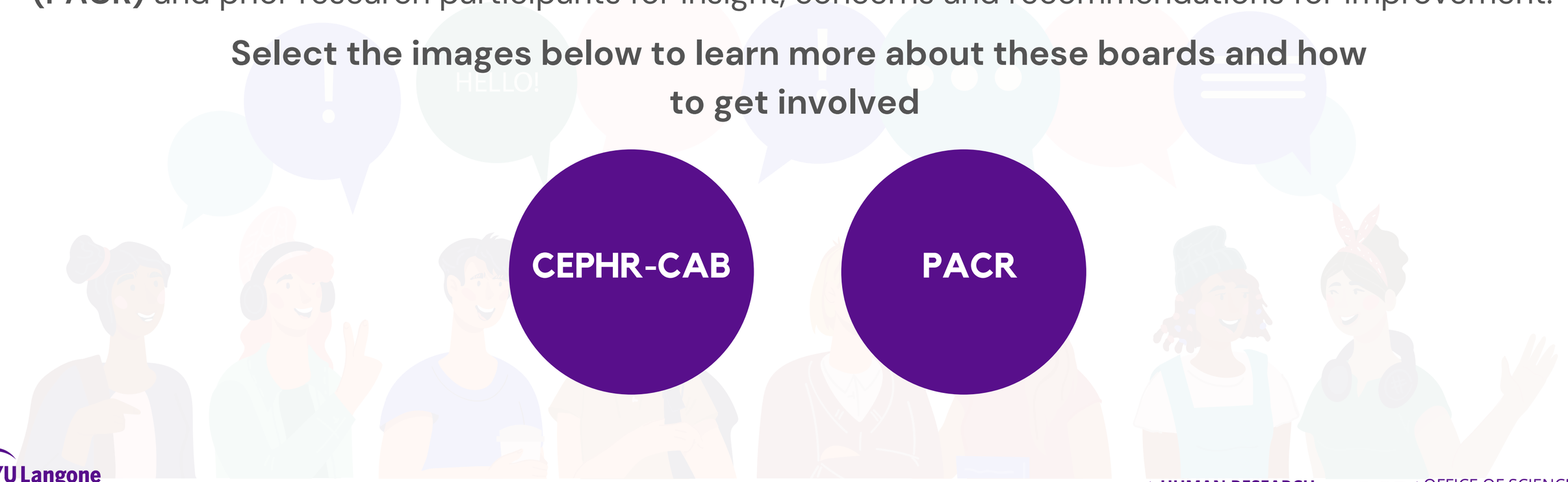
- Reviewing literature and/or providing feedback on existing research to ensure it reflects the community's experiences.

- Identifying relevant research articles or studies that may have been overlooked and share them with researchers.

# RESEARCH DESIGN

A researcher puts a plan in place to answer a question about a disease or disorder. This plan is often referred to as a protocol. During the development of this protocol, researchers may reach out to **Community Engagement and Population Health Research - Community Advisory Boards (i.e. CEPHER-CAB), Patient Advisory Council for Research (PACR)** and prior research participants for insight, concerns and recommendations for improvement.

**Select the images below to learn more about these boards and how to get involved**



# RESEARCH REVIEW AND APPROVAL

Researchers are also required to obtain approval from an **Institutional Review Board (IRB)** before any research activities take place.

The IRB reviews the protocol to ensure it has been designed in a way that decreases risk, increases benefits and protects the rights and welfare of the participants involved.

**Check out the video to learn more >>>**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# RECRUITMENT

Research protocols include information about recruitment:

- The criteria that participants must meet to take part in the study the researchers plans for finding participants

- Methods for connecting with researchers

People usually learn about opportunities to participate in research through one of the following methods:

Primary Care Doctor


Contacted through medical records (MyChart)


Random public settings (flyers, commercials, ads, etc.)

Community based advisory boards


Websites and databases such as ResearchMatch iConnect, clinicaltrials.gov

*All links provided by U.S. Department of Health and Human Services - Office of Human Research Subject Protections, clinicaltrials.gov and researchmatch.org*

# THE RESEARCH EXPERIENCE - INFORMED CONSENT

The informed consent process consists of the research team providing the the information you need regarding a study and answering any related questions you may have.

At minimum, this discussion should cover the following:

- study purpose
- study procedures
- risk and benefits
- alternatives to participation
- confirmation of participation as a voluntary decision that the participant can withdraw from at any time.


**All links provided by U.S. Department of Health and Human Services - Office of Human Research Subject Protections*

# THE RESEARCH EXPERIENCE
# HEAR FROM FORMER PARTICIPANTS

**Check out videos from the Voices of Participants Series developed by U.S. Department of Health and Human Services (HHS) – Office of Human Research Protections**


Listen to Nancy Recount Her Daughter's Participation in Research


Jeri Shares Her Insight on Participating in a Clinical Study


Abhinav and Sharat Discuss Their Experience in a Clinical Trial

**All links provided by U.S. Department of Health and Human Services – Office of Human Research Subject Protections*

# RESEARCH RESULTS, PUBLICATION AND MORE

Former participants, community and patient advisory boards are called upon by research teams to learn about research results, provide feedback, and engage in discussions about their relevance and implications.

The general public can learn about published research results via  research journals, on the internet, and on ClinicalTrials.gov.


*Links from clinicaltrials.gov*

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# THANK YOU

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