

Additional Information

You can find additional information about participating in a research protocol or find studies you may be able to join by checking information at your hospital, support groups, local library or on the internet. Here are some examples of the information you may find.

- Information about federally and privately funded clinical research www.clinicaltrials.gov
- Information about NIH Clinical Research Trials www.nih.gov/health-information/nih-clinical-research.../finding-clinical-trial
- Registry to match researchers with those who are interested in participating in research www.researchmatch.org/
- Clinical trial information for patients and general resources www.centerwatch.com
- Videos, information, FAQs and additional resources related to participation in research. www.hhs.gov/About-Research-Participation
- Froedtert Hospital clinical trial information www.froedtert.com/clinical-trials

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For additional Information contact:
Research Subject Advocate
at 414-955-8844

HRPP-QIOffice@mcw.edu

Important
Information
for
Research
Participants



Research Participation at the Medical College of Wisconsin

The Medical College of Wisconsin faculty and staff conduct a variety of human subject research projects from community based research, to record reviews, basic science, translational research, and clinical trials.

What is research?

Research is the gathering of information for the advancement of general knowledge. A research project is a group of organized activities designed to help a researcher learn more about a problem or answer a question. A research project may also be referred to as a clinical trial, research protocol, treatment trial, investigation, experimental study or a longitudinal study.

Who can participate in research?

Each research project has unique criteria that must be met to allow interested individuals to participate in the research project. Research participants may be healthy volunteers or those with a medical condition or members of a community or other group. Participation in a research project may take place in a single visit or require several visits over several days or years.

The role of the IRB

An Institutional Review Board (IRB) is a committee designed to review and approve each research project before the research can begin. The IRB's role is to ensure that rights and welfare of the research participants are protected throughout the research process.

What are your rights as a research participant?

- To be treated with respect
- To be told why the research is being done
- To know what will happen to you
- To be told about possible side effects and discomforts that may happen
- To be told if there are any benefits from participating
- To be told if other choices are available if you do not take part in the research
- To be told what sort of treatment is available if you are hurt
- To ask questions at any time
- To decide whether to participate without being pressured
- To be told about new information about the research that may affect your safety or willingness to continue participation
- To decline the offer to participate in the research
- To stop participation in research without penalty
- To know how your private information will be kept safe
- To know whom to contact with questions or concerns
- To receive a copy of the consent form

What are your responsibilities as a participant?

- Make sure you have the needed information to make an informed decision about joining or continuing in a research project
- Ask questions
- Keep research appointments or re-schedule as soon as you know you can't keep the appointment
- Follow instructions as given by the researcher or other member of the research team

Questions

In addition to discussing your rights and responsibilities as a research participant, here are some questions you may want to ask:

- What is the purpose of the research?
- Why was I invited to join the research project?
- What will happen if I participate?
- How long will the research project last?
- What are the risks of participating in the project?
- Will participating in the research benefit me?
- What are the alternatives to participating in this research?
- What happens if I decide to stop my participation in the research?
- Will there be any costs to me for participating?
- Will I be paid for participating in the project?
- How will my privacy be protected?
- What should I do if I decide to leave the research project early?
- What happens if I am injured?
- What will you do with my information?
- What happens after the research project is complete?
- Who should I call with questions about the research project or my participation in the research?