

A Helping Hand

Research is the road mankind travels to acquire new knowledge. Although the road can be difficult and sometimes dangerous, the results can be far reaching. Under what circumstances should you enter upon that road? Only you can decide in the end. However, to do so you may need some new knowledge, skills and abilities.

The research road is an unfamiliar place for most of us. Those who may invite you to join them on that road will be more familiar than yourself with its signposts and final destination. A compass and roadmap of your own could come in handy - a helping hand to balance the scales between yourself and others. GetResearchSmartSM services, such as those posted on its GRSSM website, can be that helping hand. See for yourself!



Balance in protection between self and others makes for true participation.



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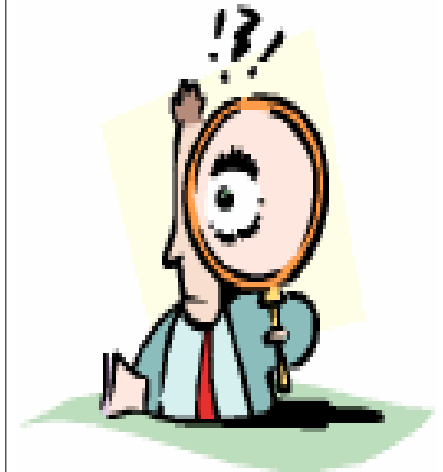
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A prepared prospect
is an investigator's
best subject!SM

**Participation in
Human Research:**

**What Should I Know
and Do Before I
Make My Decision?**



GetResearchSmartSM (GRS)

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Help When You Need It!

Overview



So, you're thinking about participation in research. What now?

Participation in research is an option not an obligation. Amongst others things, subjects deserve to (1) have explained and understand (a) the research, (b) its risks and benefits, and (c) protections; (2) be chosen without bias; and (3) either consent without force or withdraw or decline without consequence.

Problem

Protection of human research subjects rests heavily upon requirements enacted by others. They include policies of those paying for the research, procedures of research sites, and review criteria of local boards upon which investigators must rely. Review boards usually do abide by at least federal minimum standards. However, for various reasons, protections applied by others aren't necessarily required or sufficient at times. As a result, prospective subjects may assume too much and question too little upon invitation to participate.

Solution

GetResearchSmartSM provides web-based information designed with the prospective human subject in mind. Its GRSSM website includes information, tools, links to other sources, and answers to some likely questions. The GRSSM website is a springboard - a beginning not an end. The greater the research risks, the greater the value of advance preparation and alert participation.

Active Role for a Prospective Research Subject

In today's world, certain reasonable expectations exist for protection of subjects who participate in human research. These expectations are what most of us would consider to be the right things to do. They include, amongst other things, dignity for, disclosure to, and decision by subjects regarding participation. Appropriate knowledge, skills, and abilities can help a prospective subject before s/he considers consenting to participate in research. A better prepared prospective research subject can avoid over-dependence on assumptions.

Existing procedural protections are neither always required nor necessarily adequate. The GRSSM website provides information, tools, and opportunities of value to those in need.

Here are some questions to ask yourself before participation:

- What's really motivating me to consider participation?
- What are the real risks and real benefits to me?
- How does my motivation compare with the offer?
Is there a mismatch? If so, rethink the offer.
If not, are the real risks worth it to me?
- What can I do to find out about or clarify crucial facts?
A - Assume nothing (don't rely on blind trust)
S - Speak up (question the investigator and consult)
K - Know then decide (e.g., ask about prior review by a research ethics board (called an IRB), confidentiality of my private information, investigator conflicts of interest, and availability of compensation to me if an injury results from participation).
- What resources are available to help me through a decision?
Ask the investigator if his or her research institution has available a subject advocate (sometimes called an ombudsperson) or IRB person who is not part of the research staff. If so, s/he may be able to help.
- Try the self-help tools of the GRSSM website:
Review the Quick Tips, GRSSM Code, Checklist, Decision Flowchart, and/or search the Q&As.
Explore information and links to other resources.
- What publicly verifiable information exists for my research:
Institution (applicable to my investigator) or Independent or Institutional Review Board (IRB)?
- Check the GRSSM website references to government data on:
Research institutions and registered IRBs.



How the Self-Help GRSSM Website Works

Most who consider participation in research will find themselves with little firsthand experience or expertise. The purpose of self-help tools is to help even the scales by encouraging more balance between protection of and by subjects. The GRSSM website offers you a helping hand.

Knowledge

Learn from posted information and links to other sources. Print out one page summaries of reasonable expectations for investigator conduct and a checklist to help evaluate proposed research. Explore the GRSSM website to find tools like a flowchart with step by step points to consider in making a decision about participation.

Skills

Master information and self-help tools to change your personal thought process, enhance alertness, and be ready to apply these new skills in benefit to yourself.

Abilities

Know your motivation and compare it with the research of interest to you. Apply your informed alertness before and throughout your research experience. Recognize changed roles (e.g., your clinician to an investigator) that require more personal judgment by yourself and act accordingly. **A**ssume nothing, **S**peak up, **K**now then decide! **ASK**SM to help protect yourself with use of GetResearchSmartSM information.

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