Participating in Research

People with mental illnesses participate in research for a variety of reasons. For some, it offers potential access to new treatments not yet available. For others, it provides a careful reassessment by skilled clinicians and researchers. For yet others, the motivation is altruistic - to help researchers understand these severe disorders in order to develop better treatments that may benefit others.

Because research offers such promise, it becomes particularly important that all research be thoughtfully designed both to answer the research questions and to protect the welfare of research participants. While psychiatric research has generally been conducted in a highly responsible way by compassionate researchers, NAMI also recognizes that research has not always met the highest ethical standards.

You should understand how research projects are developed and how the welfare of participants is protected. There are four types of protections for research participants.

- The first is the research team itself, who are responsible for designing the study and assessing the benefits and risks of participation, and presenting that information both to the review groups and to potential participants.

- The second is the review conducted by the sponsor of the study. Currently, NIMH-sponsored research is reviewed at multiple levels for both scientific and ethical concerns. Research sponsored by other organizations or commercial firms may not receive the same degree of independent scrutiny.

- The third is the Institutional Review Board (IRB), mandated by federal law to examine all federally-funded or regulated research conducted in that institution to assure that the appropriate human subject protections are in place and that the proper information is being appropriately disclosed to potential participants.

- The fourth is the informed consent process. This is the process by which you are provided with a variety of information, including the purposes of the study, what participation will involve, the potential risks and benefits, alternatives to participating in research. You must give your informed consent to participate in research - this means you must be told all relevant information, you must understand it, and you must choose freely to participate. Informed consent is not just signing a multi-page written consent form - it is an ongoing process of sharing information with you, answering any questions you may have, and gaining your continuing agreement to participate.

- The fifth are the protections built into the actual conduct of the research - the careful clinical monitoring, the involvement of friends or family, and the focus on good communication.

When you consider participating in research, it is important that you be well informed about research in general and the specific project in particular - and that you are assured that your welfare is first and foremost in the minds of the researchers.

To help you consider participating in research, we have provided a number of resources:

- NIMH has published "A Participant's Guide to Mental Health Clincal Research"this is an excellent resource on the web and worth reading in its entirety.
- Peter Weiden, M.D., a clinical researcher and psychiatrist who serves as a key NAMI advisor has written, "Should I Participate in a Research Study" an article providing excellent guidance.
- A listing of clinical research projects this is far from a comprehensive list, but studies on this list have received a basic review by the NAMI Research Department.
- NAMI Research Policies Several of these policies deal with questions you may well want to ask the researcher - such as "will I have the opportunity to try the investigational treatment if I am not initially assigned to it?," "how will my friend or family member be involved in the consent process and the ongoing study?" and "how long will I have to consider participating and to talk it over with family or friends?"