

Appendix A – A Participant’s Guide to Alcoholism Research

You have agreed to become a participant in a research project that is investigating some aspect of problem drinking or treatment for this problem. You play a very important part in learning about HOW people drink, WHY people drink, WHAT helps people overcome their drinking problem, and WHAT can go wrong or get in the way. This *Guide* is to help you understand your role as a research participant and to answer some questions that you may have about what happens in a research project.

Question What is the difference between *treatment* and *research*?

Answer Treatment is given to an individual who has a problem with alcohol or other drugs. Treatment is generally provided in medical settings under the supervision of a physician. This means that the person receiving treatment must have a medical diagnosis of substance abuse or dependence. Research is not aimed at changing behavior or restoring health through the actions of the therapist. Research monitors change during or after treatment so that the quality or helpfulness of the treatment itself can be evaluated. Research assists professionals to improve the treatment they provide.

Question Why do people volunteer for research?

Answer The most common reasons people give for participating are—

- *To receive a new treatment:* The treatments being tested are new, or innovative, and show evidence of effectiveness. In addition, they are not available elsewhere in the community and are generally free of charge.
- *For additional medical monitoring:* Research is closely monitored to protect the health and welfare of the individual participants. This additional monitoring is to guard against problems arising from the treatment itself.
- *You want to help advance the treatment of alcoholism:* Your

participation helps advance our knowledge about treating alcoholism that can only be discovered in studies such as this.

Question How will it help me to be a part of a research project?

Answer Exceptional care is taken in developing a treatment that is to be tested in clinical research. You can be assured that you will be given excellent care.

Question What are the potential dangers of being a research subject?

Answer It is impossible to eliminate every risk in testing a new treatment. However, unnecessary risks are avoided, and many safeguards are built into the research to minimize the harm that might occur if you have an unfavorable response to the treatment. A careful review process to protect the health of human subjects is conducted before a study is approved.

Question What if I don't like the treatment I receive?

Answer Your personal reaction or opinion about the treatment you are given is important information for the professionals conducting the study. It is important to remember that some treatments take a while before they are effective. We ask that you give it a fair chance to work before you decide it isn't helpful.

Question What if I decide I don't want to continue to participate in the research project?

Answer You have a right to drop out of the study. Before making a decision to participate, we ask potential volunteers to carefully consider the commitment because it is worse for the quality of the research for a person to start and not finish than to not start at all. If you want to quit, we ask that you discuss this with the research director before you make your final decision.

Question How will my privacy be protected?

Answer Your privacy is protected by law. The information you share cannot be revealed without your consent.

Question How can I find out about the results of this research?

Answer The results of the study will not be published until all of the participants have finished. A summary of the main findings is usually provided to interested participants.