

Attachment A.1: HPOG Informed Consent Form

Health Profession Opportunity Grants (HPOG) Program Study

Informed Consent Procedures and Form

Programs often have their own informed consent or waiver forms to allow the organization or agency sponsoring the program to obtain data on the person from other agencies. For the HPOG Performance Reporting System, grantees must use the consent forms in this attachment. The procedures and script that follow can be tailored as necessary to particular programs. The mandatory HPOG informed consent form appears after the script.

Procedures for Obtaining Informed Consent

Designated program staff will provide the client with a brief explanation of the HPOG Performance Reporting System and the other uses of the data. To make this explanation as clear as possible, the information that the staff person provides to clients is presented here in two ways. First, the major points that should be explained to clients are listed in bullet fashion; and second, there is a script to show how these points can be translated into a one-on-one discussion if necessary.

Major Points to Be Covered

The following are the points that program staff should explain to clients.

- ✓ We are trying some new ways to help individuals receive training and find employment in health care.
- ✓ Research is being conducted to see how well different approaches to training for health care jobs work. This program and research are funded by the U.S. Department of Health and Human Services, and they may also fund other research on this program in the future.
- ✓ In this program, we collect some personal information from you, such as your name, date of birth, Social Security number, and your involvement in other programs. We are also collecting information about what you do in the program. We are asking for your consent so that researchers now or in the future studying how well the program works can 1) use the information about what you do in the program, and 2) use the personal information to match it with other government databases, such as the ones that include information on your wages and your further education, for example.
- ✓ All the information collected for the program or for the research studies will be kept completely private, and no one's name will ever appear in any report or discussion of the evaluation results.
- ✓ The researchers are not evaluating you; they are evaluating the program. Research findings will be expressed for the program and as summary group statistics.
- ✓ Because of the study, researchers may contact some people in the future. You may refuse to answer any of their specific questions at any time.

- ✓ Researchers and program staff using the information collected must take all necessary actions to protect your information and they will pledge their agreement under law to protect your privacy.

Suggested Standard Script for HPOG Programs to Use

Program staff can discuss the points above with participants in the following way:

This agency has received funding from the federal government for this special training program for health care jobs. Research studies are also being done to see how well the program works. The U.S. Department of Health and Human Services in Washington DC is funding this program and the research studies.

We are asking for your permission to let the researchers have information about you that they need to do their studies. This includes information about what you do in this program and some information that you might consider personal (like name, date of birth, and Social Security number). The researchers need this personal information to get information for other government data sources about your future employment, earnings, education and services you get from other programs. Some other data sources may be the government's National Directory of New Hires database, which includes information on everybody's employment and earnings, or your state's data on your post-secondary education, for example.

Your decision about whether to give permission to share your information for research will have no effect on the services, benefits, and supports you are eligible to receive in this or any other program.

All of the information used in research will be kept private. Your name will never appear in any report or with any research findings. The researchers will combine the information about everyone in the program to analyze how the program helps people find and keep a job in health care. The research reports will write about the program as a whole—the researchers might say, for instance, that “80 percent of the participants enrolled in a training program at the community college;” or “two years after training 80 percent of the participants were still working in health care.”

We and any researchers who use your information must agree to have security measures in place to protect your privacy.

Researchers may contact you in the future to ask you some questions about how you are doing. We hope you'll decide to talk with them, but you may refuse to answer any of their questions at any time.

Do you have any questions?

AGREEMENT TO TAKE PART IN THE HEALTH PROFESSION OPPORTUNITY GRANT PROGRAM AND STUDY

This program is part of a new national project to train people for health care jobs. The program is funded by the U.S. Department of Health and Human Services in Washington, DC. That agency is also funding research to study how well our program works in helping people get training and jobs. Over the next several years, researchers will be using information about people in the program to do their studies. Researchers from Abt Associates and the Urban Institute are doing the current study. Other researchers may engage in future studies. You are invited to take part in this important research.

The researchers need your permission to get information about you so they can understand the types of people in the program and how well the program is working. They want: 1) information about the training and services you get in the program; (2) information about you and your family, your education, and work history; and (3) personal data such as your Social Security number so they can get information from government sources about your future employment, earnings, education, and public benefits like welfare.

Abt Associates, The Urban Institute and future researchers will use data security procedures to keep all of the study data private and to protect your personal information. All of the information used in research will be kept private to the extent allowed by law. Your name will never appear in any report or with any research findings. The researchers will combine the information about everyone in the program to analyze how the program helps people find and keep a job in health care. Any forms or other papers that include your name will be kept in a locked storage area, and any computer files with your name will be locked and protected. Any researchers using information to study the program must follow all data security procedures and sign a privacy agreement.

Participating in research studies is voluntary. You may withdraw your permission to share data at any time. Refusing to provide permission for research now, or withdrawing permission for research later, will not affect your eligibility for any services in this program or elsewhere. If you withdraw, researchers may continue to use information that was collected about you during the period that you did give permission for research.

By participating in the study, you will help us, the federal government, and programs around the country learn about the best way to provide training and help participants get a health care job. You will be asked for information at certain times during your participation in the program and after you leave the program. You may be contacted by a researcher after you leave the program to answer some questions about your

experiences. While we encourage you to answer their questions, you may refuse to answer them.

This agreement is effective from the date you sign it (shown below) until the end of the research studies or when you choose to withdraw permission.

For questions or concerns about your rights as a research participant, call Teresa Doksum at the Abt Associates Institutional Review Board at toll-free 877-520-6835. For questions or concerns about the research call either Alan Werner (Abt Associates) at 617-492-7100, EXT 2832 (toll call) or Demetra Nightingale (the Urban Institute) at 202-261-5571 (toll call).

Statement

“I have read this form and agree/do not agree to allow information about me to be used in the national Health Profession Opportunity Grant Program research studies. I know that my participation in the research study is voluntary, that Abt Associates, the Urban Institute and any future researchers will use data security procedures to keep all of the study information private as described above, and that my name will never appear in any public report. I know that I can refuse to answer any questions researchers might ask me, and that I can stop being included in the research at any time without penalty. I understand that Abt Associates, the Urban Institute and other researchers will use my personal information to get information about me from other sources, as described above.”

PRINT NAME OF STUDY PARTICIPANT

IF YOU AGREE TO LET RESEARCHERS USE YOUR INFORMATION, SIGN ABOVE

DATE

IF YOU DO NOT AGREE TO LET RESEARCHERS USE YOUR INFORMATION, SIGN ABOVE

DATE