

**USING GENOMICS IN HEALTH CARE:
PUBLIC ENGAGEMENT STUDY
PARTICIPANT INFORMATION FORM**

Principal Investigator: Brenda Wilson, 613-562-5800 x 8261

Purpose of the Research

We would like to find out what people think about new technologies in health care. The results of this study will be used to develop advice for health service decision makers.

Description of the Research

We have approached you to take part in this study because you are eligible to receive medical care in Canada. This special workshop is part of a larger program of research looking at new technologies in health care.

Description of Procedures

This study consists of one questionnaire, in which the questions will be asked in stages. The questions are about aspects of health care related to advances in genetics. You do not need any special knowledge to answer them. You will answer some of the questions using pencil and paper, and others using a special keypad. The researcher will give you all the instructions you need. The workshop will be audiotaped. The study should take 1-1.5 hours to complete.

At the end of the questionnaire, we will give you more information about the purpose of this research.

Length of Study

The study overall is expected to take about 2 years, including several workshops and data analysis. Each participant is asked to attend one study workshop.

Possible Risks

There are no physical or other risks presented by participating in this study. You do not have to answer any questions that make you uncomfortable.

Benefits to Your Participation

There are no benefits to you participating in this study. However, the knowledge we gain from this study will be used to develop documents and other material for people who make decisions in health care policy, and professionals who provide health care.

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Research Coordinator*

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Voluntary Participation

You are under no obligation to participate in this study. You may choose to withdraw at any time, including during the workshop. You do not need to give any reason for your decision. Your decision not to participate, or to withdraw, will not affect the care that you receive at the Ottawa Hospital at this time or in the future.

Expenses

We will reimburse you the cost of transportation to participate in this study, either parking or a taxi fare, up to a \$25.00 per study workshop session.

Confidentiality

When you join the study, we allocate you a unique code. Your completed questionnaire has your code, but not your name, on it. Your signed consent form has your name on it, and it will be kept in a separate location, also under lock and key. While the study is active, the Principal Investigator will keep a master list of the participants' names and their codes, and this is kept under lock and key. If you decide to withdraw from the study, we will be able to use this master list to locate and destroy your questionnaire.

When we have gathered all the answers, we will enter your replies onto a computer database for analysis. The computerised data will not contain your name or other identifying information. The answers written on paper will be kept in a locked cabinet. The computer data will be saved in password-protected files. Only selected investigators and their research team will be able to access the paper and computer files. Once the study is complete, and no further analyses are required, we will remove the codes from all computerised data, so that the data will be completely and permanently anonymous.

All personal health information will be kept confidential, unless release is required by law. When the results are analyzed and written in scientific papers, we may include some direct quotes from answers given in the questionnaires. However, they will be presented in a way which cannot be linked to any given participant. The study data will be kept for 15 years after termination of the study and then destroyed. The Ottawa Hospital Research Ethics Board and the Ottawa Health Research Institute may review your relevant study records for audit purposes.

Questions

Ms. Samantha Craigie is the Research Coordinator responsible for running this study, and she is the first point of contact for all questions. If you would like to speak to the investigator in charge of this study, you are encouraged to call Dr. Brenda Wilson at 613-562-5800 ext 8261. She will be happy to talk to you without any obligation on your part.

If you have any questions regarding your rights as a research subject, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at 613-761-4902. The chairperson cannot provide any medical information with regard to this study.