

Health and Wellbeing Survey

Participant Information Sheet

Health and Wellbeing Survey

You are being invited to take part in a research study. Before you take part, it is important that you understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. If anything is not clear or if you would like more information, please ask. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Every day decisions are being made on how to best use our limited healthcare resources. This study is being carried out to help improve how this can be done. Members of the general public in Ireland, including you, are asked to help with this study. The questions are about the different views of people regarding health and illness.

The research is being organised by the National University of Ireland, Galway (NUI Galway) and is funded by the Health Research Board.

Why have I been chosen?

We are seeking adult participants from the general population of Ireland. Your address has been chosen at random from a list of all addresses in Ireland, to ensure the results are representative of the country as a whole. We would like to interview one adult in your household.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to participate, you will be asked to sign a consent form but you can still withdraw at any time. You will be given a copy of the signed consent form and a copy of the information sheet to keep.

If you decide to withdraw, then any information that you have already provided will be destroyed. You do not have to give a reason for not taking part or for withdrawing.

If I agree to take part, what happens next?

If you agree to take part, you will complete an interview survey, which is likely to last between 30 and 45 minutes. The interview will take place in your home at a time convenient to you.

You will receive a €10 voucher in appreciation of your co-operation. A computer will be used to provide instructions and to note your responses.

You will be asked to think about some health states you may or may not have experienced. These health states will be described in terms of aspects such as mobility and pain. We will ask you to consider how it would feel to be in these health states for a certain amount of time. There are no right or wrong answers – we are simply seeking your views.

What are the possible benefits of taking part?

You will be contributing to research that could help decision makers to better understand the preferences of members of the general population and therefore to make better decisions about funding care.

What are the possible disadvantages of taking part?

Some participants may feel uncomfortable when asked to think about scenarios involving illness and death. However, previous research in this area has shown that participants are generally interested and engaged when taking part in these types of exercises. Remember – you are free to withdraw from the interview at any time.

Who can I contact if I have any concerns about the survey?

Should you wish to raise a concern or complaint regarding your treatment by researchers or any other aspect of the study, please contact Professor Ciaran O’Neill (details below).

Will my taking part in this study be kept confidential?

All information that is collected during the course of the research will be kept strictly

confidential under the terms of the data protection legislation. Your name will not appear in any reports or publications that may come from the research. Information given in the questionnaires will only be identifiable by ID numbers, and only the researchers will be able to match the ID number with a name.

What will happen to the results of the research study?

The results will form the basis for a new ‘value set’ for Ireland, which can be used to make decisions on health care that reflect the preferences of the Irish public. Articles reporting and discussing the results will be published in academic journals. The results will also be presented and discussed at research conferences. The anonymised data collected during the course of the project may be used for additional or subsequent research and analysis.

Who has ethically reviewed the study?

The project has been reviewed by the Research Ethics Committee in the National University of Ireland Galway. If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie.

Contact details of research team

If you have any queries, please contact one of the research team:

Text/phone: 086 020 4132 or 086 020 4127 or 091 492866

Email: Anna Hobbins a.hobbins1@nuigalway.ie

Luke Barry luke.barry@nuigalway.ie

Prof. Ciaran O’Neill ciaraneoneill@nuigalway.ie

Post: Research Team, Room 2008, ILAS Building, NUI Galway.