



Information sheet: Valuing health

Thank you for expressing an interest in this study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it will involve for you. Please read the information carefully. You can talk to family and friends about taking part in the study if you wish. Please contact us if there is anything that is not clear or if you would like more information (contact details will be provided in the end of this information sheet).

What is the purpose of the research?

The purpose of this research is to find out how people value different aspects of health. This means that we would like to find out how good or bad you think living with different levels of ill health would be. This will provide important information that can help support decision making in health and social care, for example for the Department of Health and Social Care and NICE, the National Institute of Health and Care Excellence.

Why are you asking me?

We wish to recruit 1430 members of the general public. We are looking for people from the UK of different ages, gender, ethnicity and socio-economic group and to have people with and without health problems.

Do I have to take part?

No, you do not have to take part. Taking part in the research is up to you. If you do not want to take part it will not affect you in any way.

What should I do if I would like to take part?

If you would like to take part, please follow this link to complete the application form. You will be asked some questions about you and to provide your name, email address and phone number so that we can contact you to arrange the interview:

<https://www.liberatingresearch.com/projects/136>

If you are selected to take part we will email you a link to choose an interview date and time that is convenient for you. When you have chosen your interview date and time, we will ask you to complete a consent form online, saying that you consent to being interviewed. We will phone you to arrange the interview if you do not provide an email address, and may phone you if you do not respond to the email.

We are sorry that some people may not be able to take part. This is because we may already have enough people taking part with your age, gender, ethnicity or socio-economic group (using postcode). We will let you know as soon as possible whether or not you have been chosen to take part by email, at the very latest by 31st August 2023.

You can withdraw at any time up to and during the interview. After you have completed the interview you will not be able to withdraw. We will be unable to remove your data at this point as the data will be anonymized so we are not able to identify your answers. This means that your data will be included for analysis.

Will I be paid for taking part?

If you are selected to take part you will be compensated with **£50 (paid by bank transfer) or a £50 Amazon voucher**. You can choose whether you prefer money (by bank transfer) or the voucher. The money or voucher will be paid to you within 10 working days of you confirming how you would like to be paid, after taking part.

If you withdraw from the study during the interview you will still receive the money or vouchers. If you agree to participate but then do not start the interview, you will not receive the money or vouchers.

If you receive state benefits (for example Universal Credit) and want more information on how payment for your involvement might affect these, you may wish to contact the Citizens Advice Service <https://www.citizensadvice.org.uk/benefits/> for more information.

What will happen if I am selected to be interviewed?

You will be invited to an interview that will last for around 40 minutes (between 30 minutes and one hour) with one interviewer. The interview may be observed by members of the research team to provide feedback to the interviewer for training purposes. We will arrange the interview at a time which works for you. You can choose whether you prefer to be interviewed **online or in person**.

You will provide consent to be interviewed when arranging the interview. Liberating Research are recruiting and scheduling interviews on our behalf.

If you choose to undertake the interview **online** you will take part using Zoom, a videoconferencing software. You will need a computer, laptop or tablet and internet connection. We also ask that you switch your camera on. We do not allow any friends or relatives to attend the interview with you.

If you choose to undertake the interview **in person**, you will take part in a public space, for example a community centre, sports hall or on University premises. The interview will involve the use of a laptop provided by us. During the interview we will follow the latest COVID-19 government guidelines, and these still apply even if you are fully vaccinated for COVID-19. If the government guidelines require social distancing, you and the interviewer will each have a laptop and all equipment and furniture will be wiped between interviews. Hand sanitiser will be available. A friend or relative can accompany you to the interview site, but they will not be allowed into the interview with you and will be asked to wait in the waiting area. There will be toilets on site. We are unable to offer refreshments during the interview.

You will be asked to show the interviewer a copy of your photo identification at the start of the interview, although no copies will be made of this identification.

At the start of the interview we will ask you to answer questions about you and your health. You will not be discussing private or sensitive health information during the interview.

In the next part of the interview we will ask you whether you would prefer to live with less than full health for a given number of years compared to living without any problems (full health) for the same number of years or fewer years. You will be shown practice questions and then asked to do this for ten different states of ill health. These are all hypothetical (i.e. imaginary) questions.

We will then ask you questions about what you thought of the interview. We will ask you questions related to doing the task and the conduct of the interview so that we can understand how you found doing the tasks. We will also ask some additional questions about you and your health.

Before the interview we will email you a link to this information sheet. You will be asked to complete an online consent form prior to the interview. If you would like to instead have a printed copy of the information sheet or would like to apply over the telephone, please contact Stephanie Foy at Liberating Research

on 0203 983 2640 and we are able to do so. You will also be asked whether you would like to receive your £50 thank you payment in money (bank transfer) or Amazon vouchers. You will be asked to provide payment details for money (bank transfer) or an email address so that we can email the vouchers to you.

What are the possible risks of taking part?

The tasks refer to a variety of imaginary health states as well as death which may have an impact on how you feel. You will be able to stop the interview at any time if you wish and your data will not be included in the study.

There is a low risk involved in taking part in the research. There is a risk of exposure to COVID-19 wherever there is movement around of individuals, but we have implemented COVID-19 government guidelines to minimise this risk.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. The information you give in the interview will not be used in any way that could identify you. We will allocate a code to your responses that will be used to uniquely identify any data you provide in the interview. Your name will not be linked to the data. Your personal details (in the application form to take part, the consent form and in the emails you send to say you would like to take part) will be kept separately from other information you provide during the interview.

Who is the data controller?

The University of Sheffield is the sponsor for this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

As we will be collecting some data that is defined in the legislation as more sensitive (information about your health and ethnicity), we also need to let you

know that we are applying the following condition in law: that the use of your data is 'necessary for scientific research purposes'.

The University of Sheffield Data Protection Officer is Luke Thompson and you can contact them for further information at dataprotection@sheffield.ac.uk.

Who will have access to the data and where will it be held?

Your contact details will be shared with the study team who are arranging and conducting the interviews. They will use your contact details (name, email address and phone number) for the purposes of contacting you about this study, to check your eligibility, schedule your interview, collect your details to pay you the money or vouchers, and to contact you at the time of the interview if required. You will be asked when you provide your details whether you want to also be contacted about taking part in other studies by Liberating Research. People who do not register their details to be contacted for other studies by Liberating Research will have all personal data permanently deleted at the end of the study.

You will be asked to schedule your interview online using a scheduling tool (Calendly). The scheduling tool will store your personal information (including but not limited to your interview date and time, name, phone number and email address) for the duration of the study in order to send you confirmation and reminder emails and text messages about the study. The scheduling tool will not use your information for any other purpose and will permanently delete your personal data at the end of the study. For more information about how your data is protected, please see the privacy policy that will be included in your scheduling email.

All anonymised data collected during the interview will be held in confidence at the University of Sheffield and a copy will also be stored by the EuroQol Group, the funders of the research. It will be used for the purpose of this research by the research team, and will be made available for data quality checking. The anonymised data may also be used by other researchers for the purposes of future research and learning.

What will happen to the results of this research?

This will provide important information that can help support decision making in health and social care, for example for the Department of Health and Social Care and NICE, the National Institute of Health and Care Excellence. The results may be published in academic journals, presented at conferences, and

be presented on websites. Nobody will be able to identify you in any reports or publications.

What if something goes wrong?

If by participating in this research you have any questions, please contact the study team (details given at the end).

If you find some of the questions upsetting, or if you wish to seek advice or reassurance about your own health, then contact NHS Choices (Tel: 111) or your GP if required.

If you want to complain or have any concerns about the way the study has been carried out, please contact the Lead Researcher Donna Rowen at d.rowen@sheffield.ac.uk.

If you feel your complaint has not been handled properly, you can contact:

Mark Strong, Dean of School of Health and Related Research (ScHARR), University of Sheffield, Regent Court, 30 Regent Street, Sheffield S1 4ED. Tel: 0114 222 2992.

If the complaint relates to how your personal data has been handled, you can contact Luke Thompson, The University of Sheffield Data Protection Officer dataprotection@sheffield.ac.uk Further information about how to raise a complaint can be found in the University's Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>. If you feel that your complaint has not been handled to your satisfaction, you can contact the Information Commissioner's Office.

Who is funding the research?

This research is funded by the EuroQoL Research Foundation.

Has the research been approved by an ethics committee?

This study has been ethically reviewed and approved by the School of Health and Related Research Ethics committee at the University of Sheffield. The reference number for the study is: 048042.

If you have any questions about the research please contact:

The research team at valuing_health@sheffield.ac.uk