

Patient Information Leaflet

Patients' Preferences for Health

You are invited to participate in a study which will explore **“Patients' Preferences for Health”**. Before you decide whether you wish to take part or not, we would appreciate you reading this information sheet.

What is the purpose of this research?

In general people have preferences over being in one state of health over another. This can often be a preference to have good health over bad, or to be in good health for so long and to be in less well health for a shorter period of time. By asking the public in Ireland to make these decisions or trade offs we can say something about the general preferences of people in Ireland.

Preferences gathered in this way can then be used to guide choices around decisions in relation to health. Using preferences from the general public is deemed to be a fair way of deciding on how to assign healthcare resources.

However, it is likely that a person's experience of being in a health state will alter their preferences compared against those who are only imagining being in that state.

This work proposes to quantify the differences between patients' valuations having experienced and not experienced health states and the general population by looking at the preferences of patients with Cystic Fibrosis and Multiple Sclerosis.

Who is being asked to participate in this Research Study?

We are looking for participants with Cystic Fibrosis or Multiple Sclerosis, and the people asked will represent what all people living in Ireland with these conditions think and therefore there will be a mix of people young and old across all sections of society, and severity of conditions.

Patients' Preferences for Health

Principal Investigator: Dr. Roisín Adams

Email address: ROADAMS@tcd.ie

Research Associate: Dr. Stephen Erskine

Email address: erskines@tcd.ie

What will my participation in this Research Study involve?

If you agree to participate in this study, you will go through a series of simple tasks that will be outlined to you by a trained person. These tasks will involve completing a questionnaire and then making various choices between scenarios presented to you. These tasks may take up to 1 or 1.5 hours. This is the extent of your involvement; there will not be a requirement from you to participate in another interview after this. However, you will be given a contact in case you have any further questions.

What will happen if I volunteer?

If you volunteer, we will contact you directly to fill in a consent form and arrange an interview time convenient for yourself.

When the interview is finished, we will pay you €20 to reimburse you for the time spent completing the survey.

What will this information be used for?

This information will be used to create a set of values which can be compared against the choices of the general population in Ireland have chosen. This can be used for a variety of purposes, one such will be included in the analysis that decision makers (Department of Health or the Health Service Executive) use to make decisions.

This information, in an anonymous form, may also be used in future work examining what people living in Ireland have chosen in relation to health.

What is the nature of my personal details that will be stored?

This study does not require your personal details such as address and name to be stored in any way. This information will be used only to locate you as a participant in this study. We may request further information about your condition (with your consent) from CF Ireland or MS Ireland. This would be done to ensure that we get a representative sample of patients. Following your agreement to participate, a number will be assigned to the information you have provided and this will be stored in a secure database for the study.

Patients' Preferences for Health

Principal Investigator: Dr. Roisín Adams

Email address: ROADAMS@tcd.ie

Research Associate: Dr. Stephen Erskine

Email address: erskines@tcd.ie

May I withdraw, at a future date, my consent for participation in this study?

You may withdraw, at any time, your consent for participation in the study. If you wish to do so all data pertaining to you will be destroyed.

Patients' Preferences for Health

Principal Investigator: Dr. Roisín Adams

Email address: ROADAMS@tcd.ie

Research Associate: Dr. Stephen Erskine

Email address: erskines@tcd.ie



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Patient Consent Form

Patient Preferences for Health

Please complete your details below and sign and date the declaration to give your consent to be included in the Patients' Preferences for Health study.

Patient's name:

Patient's date of birth:

Address:.....

Study number:

VOLUNTARY CONSENT

I have read, considered and understood the Patient Information Leaflet about the Preferences for Health in Ireland. The purpose of the study has been explained to me in full and all of my current questions have been answered. I understand that I am encouraged to ask questions about any aspect of my participation in the study. I understand that a copy of this consent form will be given to me.

I agree to the collection and collation of the information I have provided for this research.

By signing below, I agree to participate in the Preferences for Health Study.

Participant's Signature

Date

You may withdraw, at any time, your consent for participation in the study. If you wish to do say all data pertaining to you will be destroyed. To formally withdraw your permission for participation, you should provide a written and dated notice of this decision to the principal investigator of the study at the address listed in the footer of this consent form.

Patients' Preferences for Health

Principal Investigator: Dr. Roisín Adams

Email address: ROADAMS@tcd.ie

Research Associate: Dr. Stephen Erskine

Email address: erskines@tcd.ie

CERTIFICATION OF INFORMED CONSENT

I certify that I have explained the nature and purpose of the Preferences for Health study to the above-named individual, and I have discussed the possible uses of this information. Any questions the individual has about this study have been answered or have been noted and will be responded to.

Printed Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

Patients' Preferences for Health

Principal Investigator: Dr. Roisín Adams

Email address: ROADAMS@tcd.ie

Research Associate: Dr. Stephen Erskine

Email address: erskines@tcd.ie