**Participant Information Sheet & Consent Form**

**Study Title:** **Attitudes of geriatricians in Europe towards euthanasia and assisted suicide.**

**Study Investigators: Dr Patrick Crowley, Prof Shaun O’Keeffe, and Dr Rónán O’Caoimh**

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve, so as to enable you to make an informed choice.

**Procedures**

As a member of the European Union Geriatric Medicine Society, you are being asked to complete a questionnaire designed to assess your attitude towards euthanasia and assisted suicide. The questionnaire will also seek some information regarding your demographic details and your professional experience with end-of-life care.

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions. All information you provide will be confidential and your anonymity will be protected throughout the study.

You maintain the right to withdraw from the study at any stage up to the point of data submission. At this point your data will be collated with that of other participants and can no longer be retracted.

**Data Management**

All responses received will be anonymized. No information that might lead to the identification of a study participant will be used in the statistical analysis or in any published report. All responses received shall be destroyed upon completion of the study. Data protection laws and principles will be strictly adhered to.

**Ethical Approval**

Ethical approval for this research study has been granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals in Ireland.

**Risks**

We do not anticipate any negative outcomes from participating in this study**.** Should you experience distress arising from participating in the research, the contact details for support services provided below may be of assistance.

**Funding**

No funding has been used to conduct this study

**Study enquiries**

If you have any queries about this research, you can contact me at Dr Patrick Crowley, patrickdjcrowley@gmail.com. The study supervisor is Dr Rónán O’Caoimh, who can be contacted at rocaoimh@muh.ie.

**Consent to participate**

If you agree to take part in this study, please complete the following section.

Do you consent to participate in this study?

Yes ☐

No ☐

**Data Protection Notice**

At Mercy University Hospital, we treat your privacy seriously. Any personal data which you provide to the hospital will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation. This notice sets out details of the information that we collect, how we process it and who we share it with. It also explains your rights under data protection law in relation to our processing of your data.

## Who we are

Throughout this Notice, “we”, “us” and “our” refers to Mercy University Hospital, as study.

## How we will use your personal data

By participating in the study and performing the study exams, information from you (also called “personal data”) will be collected for the study purposes mentioned in the Subject/Patient information leaflet above. This personal data includes, for example:

−      Information that directly identifies you (such as your name, and your year of birth);

−      Your gender, ethnic and racial background;

−      Information on your health and medical condition including your medical history;

−      Your treatments and your response to treatments,

\_ Information from the medical records held by the hospital/general practice

Personal data collected at any time during the study will be kept strictly confidential. Every person that has access to your data (that is kept at the sites of investigation) is subject to professional secrecy and confidentiality.

## Who will access my personal data?

Your data will only be accessible to clinical site employees (where relevant), the study researcher and site staff and the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) so that they can check if the study is being conducted to the best standards.

Results of the study will be provided to the ethics committee approving the study in compliance with national and international regulations on clinical studies.

## The purpose and legal basis for collecting your data

Any personal data you provide to us during the course of this study will be processed fairly and lawfully.

Signing the Informed Consent Form means that your personal will be used for the purposes outlined in the Patient information leaflet (PIL).

Personal data collected during this study and the results of the study may be presented for scientific purposes. However, you will never be identified individually during these presentations. Your identity will not be revealed in any reports or publications.

The study Researcher and the members of the study’s team will use your personal data within the scope defined above. If the study researcher or study team wish to use your data for a purpose other than the purpose specified, the researcher must contact you again to give you more information and ask your permission to use your data for the new purpose.

The General Data Protection Regulation allows us to process your data because you have provided your consent. You are entitled to withdraw your consent at any time.

## How long we will keep your data

The personal data collected in the study will be kept for a period of up to 5 years after the end of the study. Thereafter, they may be stored for a further period of time for legal reasons (e.g. revised retention obligations), or more if required by law.

## Your rights

You have various rights under data protection law, subject to certain exemptions, in connection with our processing of your personal data, including the right:to find out if we use your personal data, access your personal data and receive copies of your personal data;

* to have inaccurate/incomplete information corrected and updated;
* in certain circumstances, to have your details deleted from systems that we use to process your personal data or have the use of your personal data restricted in certain ways;
* to object to certain processing of your data by MUH;
* to exercise your right to data portability where applicable (i.e. obtain a copy of your personal data in a commonly used electronic form;
* to withdraw your consent to the processing of your data at any time without giving a reason by notifying your decision to the study Researcher. This will not affect the lawfulness of processing data about you based on your consent before the withdrawal. If you withdraw your consent for data processing, your participation in the study stops and no further data will be collected from you. Your study Researcher will present you the options you have concerning your personal data.

Along with study withdrawal, you have the right to request the deletion of data about you if your data are no longer necessary for the purposes of processing or there is no other legal ground for their further processing.

If you wish to exercise any of these rights, please address your request to the study Researcher, Dr Rónán O’Caoimh.

## Questions or Complaints

If you have any queries in relation to this study please contact Dr. Rónán O’Caoimh email: rocaoimh@muh.ie or phone: 086 3241795

Mercy University Hospital is the Data Controller for this Research Project. If you have any complaints in connection with our processing of your personal data, you can contact MUHs Research Manager, e.flanagan@ucc.ie

You also have the right to lodge a complaint with the Data Protection Commission if you are unhappy with our processing of your personal data. Details of how to lodge a complaint can be found on the

Data Protection Commission’s website ([www.dataprotection.ie](http://www.dataprotection.ie)), or by telephoning 1890 252 231.

I have read and understood the MUH Data Protection Notice:

Name of Subject \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of Subject\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of Investigator \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of Investigator \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_