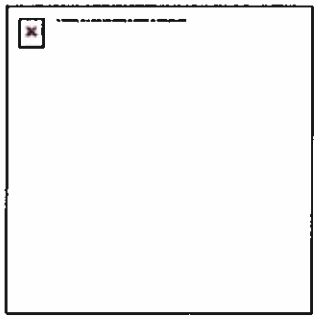
Van: Madeleine Jemima Grace Archer <madeleinejemimagrace.archer@hdr.qut.edu.au>
Verzonden: donderdag 7 september 2023 1:13
Aan: PR ANTWERPEN
Onderwerp: International research study on euthanasia regulation
Bijlagen: Approved_health_professionals_informed_consent_form (3).docx

Dear Orde der Artsen Antwerpen

My name is Madeleine Archer from the Queensland University of Technology (Australia), and my research team is undertaking a research project about euthanasia in Belgium. The project aims to learn from your experiences of euthanasia in Belgium to inform a comparative study with Australia, where euthanasia is relatively new. The project will propose an optimal holistic regulatory framework for euthanasia in Australia, with recommendations for improvements to euthanasia regulation in Belgium as well. The project is funded by the Australian Research Council Future Fellowship Scheme.
Researchers from the End-of-Life Care Research Group (VUB and Ghent University) are co-investigators on this research project.
We are inviting health professionals (doctors, nurses, and professional caregivers) who are proficient in English or Dutch to participate in a semi-structured interview by private Microsoft Teams video-conference session or telephone. The interviews will be recorded, are estimated to take around 60 minutes, and will aim to obtain views on how regulation affects decision-making about euthanasia, and how regulation could be improved. To be eligible to participate, health professionals must have been involved in the euthanasia assessment of at least two patients in the past year.

Would it be possible to advertise this study among the health professionals within your organisation?

I attach the information and consent form, which contains information about the study, and what participation would involve. I can also provide this in Dutch.
Please do not hesitate to contact me if you have any questions about the study. You can view the project website here: https://research.qut.edu.au/voluntary-assisted-dying-regulation/



Home - Optimal Regulation of Voluntary Assisted Dying

Led by Professor Ben White, this research project explores regulation of end of life care and voluntary assisted dying (VAD) and will propose a new optimal...

research.qut.edu.au

Also note that this study has been approved by the Brussels University Hospital Medical Ethics Committee (EC-2022-057).

Many thanks for your consideration of this request.

Kind regards

Madeleine Archer
Study Coordinator

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INFORMATION AND CONSENT FORM

VRIJE UNIVERSITEIT BRUSSEL

OPTIMAL REGULATION OF EUTHANASIA: BELGIAN CASE STUDY ON EUTHANASIA

You are asked to participate in the study Optimal Regulation of Euthanasia: Belgian Case Study on Euthanasia. Your participation is voluntary: you are not obliged to take part and if you refuse, this will have no (negative) consequences for you. Take enough time to decide whether or not you want to participate. You can also ask the research team questions at any time if something is not clear. You can stop your participation at any time (in writing or orally) and you do not have to give a reason for doing so.

Below you can find more information about the study and how it will proceed. If you would like additional information, you can always contact the research team.

Contact details

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1. Purpose of the study (PhD)

We invite you to participate in a scientific research study and PhD project being led by researchers at the Queensland University of Technology (QUT) and Vrije Universiteit Brussel (VUB) on how people make decisions about euthanasia.

The purpose of this research is to better understand how people make decisions about euthanasia in Belgium. Euthanasia is heavily regulated in Belgium, through a variety of instruments including laws, policies, and professional standards. We are interested in how individuals involved in euthanasia, including health practitioners navigate these rules and standards, how regulation affects health professionals, how decisions are made, and what affects individuals' experiences of the euthanasia process. This study aims to identify how these components of regulation work together in order to influence decision-making, in order to produce a realistic picture of the Belgian euthanasia process. One of the aims of this study is to make suggestions for how decision-making about euthanasia in Belgium can be improved, which may have implications for clinical practice.

This study is part of an international project conducted in Australia, where euthanasia is very new. Australia can learn from the Belgian experience, and the findings from this study may also be used to develop better laws, policies and decision-making processes for euthanasia in Australia.

2. Who can participate

You are invited to participate in this research project because you are a health professional (doctor, nurse or professional caregiver) who is likely be able to provide insight into how regulation influences euthanasia. To be eligible to participate, you must be proficient in English or Dutch and have been involved in the euthanasia assessment of at least two patients in the past year.

3. Practical conduct of the study and the interview

Your participation will involve a semi-structured interview to occur by MS Teams video-conference session, or alternatively, telephone, that will take approximately 60 minutes. Interviews will be carried out by trained interviewers. The interview will be audio and video recorded (if conducted by MS Teams) or audio recorded (if conducted by telephone) so that it can be transcribed and analysed. It is not possible to participate in the interview without being recorded. If you choose to participate, you will also be asked to provide responses to a written questionnaire which collects data relating to your age, gender, location and setting of primary practice, employment status, nature of profession and areas of practice, years of practice and information relevant to your cultural background.

The interviews aim to understand how regulation influences euthanasia by exploring which actors and tools of regulation affect decision-making about euthanasia and how they affect decision-making. You will be asked about improving current regulation (including principles that should guide regulation). The interview will include questions such as: *how do policies or ethical codes influence your decisions about euthanasia? What are the current strengths and weaknesses of the existing euthanasia regulation?* If you agree to participate you do not have to answer any question(s) you are uncomfortable answering. If relevant and appropriate, we may also request access to non-public tools of regulation influencing decisions and euthanasia, including policies and training resources. You may decline to provide this access.

The recording of your interview will be made available to a professional transcription service, who will provide the research team with a transcription. The transcription service will be required to sign a confidentiality agreement. If a translator is required to translate the recording, they will also be required to sign a confidentiality agreement. Only the research team members, the transcription service and professional translator (if required) will have access to the recording.

To make sure that our records are factually correct, we will send you a copy of the transcript of your interview for your review. We ask that you contact us within two weeks of receiving your transcript if you wish to clarify the transcript, to listen to the recording, or to engage in one further interview or withdraw from the study. If this period elapses and you have not made comment, we will presume that you are satisfied with the transcript. If you withdraw from the study, your name will be removed from the data and we will destroy the recordings and transcript as soon as practicable.

If you approve the transcript, to maintain your privacy, we will destroy the recording as soon as the transcript is deemed satisfactory. We will remove your name and any identifying details from the transcript within two weeks of its being deemed suitable.

Interviews will be conducted from Australia, by both Belgian and Australian members of the research team, which means that your personal data will be accessible outside of Belgium and stored securely in Australia. Any risks will be reduced by using a private MS Teams link, and the interviewer will only use your first name in the interview. Only the research team will be able to access the research data.

If you would like to receive overall feedback about the results of the study, we will provide you with a short summary of results. You can obtain these results by communicating this wish to the researcher team at the end of the interview. The summary will be provided once the analysis of all interviews has been completed and final results determined. Resources and project findings are also available through the project's website, which you can visit here: https://research.qut.edu.au/voluntary-assisted-dying-regulation/

4. Possible risks and inconveniences

There are minimal risks associated with your participation in this study. There is a risk that you might experience some discomfort or distress during the interview because euthanasia is a sensitive topic and may invoke strong feelings for some people, however we note that you are being interviewed in your professional capacity.

Should you experience discomfort or distress as a result of your participation in this study we will direct you to appropriate supports including:

- Community Help Service for anonymous and confidential support 24/7 on 02 648 40 14
- Zelmoordlijn crisis line on 1813
- A qualified health professional such as the VUB study psychologist.

We will not disclose any information about your participation in this study, and keep the research data confidential, unless we believe that imminent danger is posed to someone in the immediate future. This is extremely unlikely. In any event, information disclosed in an interview cannot be used as legally admissible testimony.

5. Possible benefits

This study aims to generate suggestions to improve euthanasia regulation in Belgium and in Australia. Whilst decisions about any changes flowing from the findings of this study rests with other persons, your participation may provide you with an opportunity to reflect on how regulation influences euthanasia and your practice, and to voice your perspectives in an interview. The findings of this study may be useful in your work.

6. Privacy and confidentiality

First of all, you should know that, as a research team, we have a **duty of confidentiality** with regard to the data collected. This means that we undertake, for example in the context of a publication or a conference, never to reveal your name or any other data that could identify you. Nor will individual results ever be published. A Data Processing Agreement has been concluded for this study.

Secondly, in the course of this investigation personal data will be collected about/from you. The collection and processing of your data is possible because we carry out scientific research and we receive your **express consent**.

The collection and processing of data is in accordance with the legal principles imposed by the new European **General Data Protection Regulation** (GDPR or AVG), which has been in force since 25 May 2018. QUT provides the same guarantees as the GDPR in respect of this study.
We supervise the correct processing of your personal data and the associated information obligation. This obligation to provide information means that we have to inform you about:

a. What **personal data** we collect from/about you, in particular: video or audio recordings, your name, your e-mail address, telephone number (if applicable), field notes, demographical information (including your age, gender, location and setting of primary practice, employment status and profession, areas of practice, years of experience, and whether there is anything you would like to share regarding your cultural background).

b. That QUT (Queensland University of Technology, 2 George St, Brisbane City, Queensland, Australia) acts as controller of your data.

c. That QUT and VUB (Vrije Universiteit Brussel, Pleinlaan 2, 1050 Brussel, KBO 449.012.406) act as processers of your data.

d. That the data are collected and processed for the purpose of the aforementioned study. In accordance with the relevant legislation:
   - Interview transcripts and completed demographics questionnaires will be securely retained for 5 years after the project is completed (on the later of 24/06/2027 or when publications associated with the project have been completed), consistent with the Queensland University Sector Retention and Disposal Schedule clause 601.3/C150.
   - Hard copy consent forms will be securely retained for 15 years after the project is completed, consistent with the Queensland University Sector Retention and Disposal Schedule clause 601.2/C11.
   - The interview recording will be destroyed as soon as the interview transcript is deemed satisfactory.
   - The masterlist of participants will be destroyed at the end of the study (on the later of 24/06/2027 or when publications associated with the project have been completed).

e. That we may only use your personal data for scientific purposes.

f. That you have the right to access and correct your data. You also have the right to erase your data, to limit their processing, to object to their processing and to transfer your data to third parties. If you have any questions, please contact the research team

g. You have the right to withdraw your consent to the processing of your data at any time. The withdrawal of consent does not affect the lawfulness of the processing of the data obtained prior to the withdrawal of consent.

h. Your data will be shared with partners outside the European Union (Queensland University of Technology, Research University). We guarantee that an equal level of protection will apply as that imposed by the General Data Protection Regulation.

i. Your data will be stored and secured in accordance with the guidelines of QUT.

j. If you wish to exercise your rights or if you have any further questions regarding your rights and the processing of your personal data, you can always contact the VUB **Data Protection Officer:** dpo@vub.be.

k. That in order to guarantee your privacy the following protection measures will be taken:

   - The data collected are not anonymous in the first phase, which is why they are converted into codes (pseudonymisation) as soon as possible. This is a second dataset that is created

where it is no longer possible to identify you directly. A "translation key" is therefore created which can convert the codes back to their original meaning. Only the research and team (Luc Deliens, Madeleine Archer, Ben White, Kenneth Chambaere, Lindy Willmott) have access to this key and thus to the non-anonymous data. This ensures that only the research team can link this data to you as a person. The encryption key is stored separately and securely and deleted at the end of the project, which anonymizes the data.

- The audio and video recordings made during the interview are converted to transcriptions as soon as possible and the audio and video recordings are then deleted.

- Your data will only be stored on the QUT Research Data Storage Solutions ('RDSS'), a secure repository which is designed by QUT specifically to securely house research data. RDSS has strict access conditions and offers a high degree of protection. Your data is therefore only stored on the local computer of the researcher before it is immediately uploaded to RDSS, and then immediately deleted from the researcher's local computer, and your data is never forwarded by e-mail.

l. Finally, you also have the right to **complain** about how your data is being handled. You can do this with the Belgian supervisory authority responsible for enforcing data protection legislation, in particular:

Gegevensbeschermingsautoriteit (GBA)
Drukpersstraat 35
1000 Brussel
Tel. +32 2 274 48 00
e-mail: contact@apd-gba.be
Website: www.gegevensbeschermingsautoriteit.be

7. Statement by the Researcher

I, the undersigned [Archer, Madeleine], researcher, declare that I have provided the required information about this study orally, as well as a copy of the information document to the participant.

I confirm that no pressure has been exerted on the participant to have him / her consent to participate in the study and I'm willing to answer any additional questions.

I confirm that I work in accordance with the ethical principles as stated in "The Code for Scientific Research in Belgium" and the ethical principles within my specific research discipline.

I confirm that I work in accordance with the legal obligations regarding the correct processing of personal data as stated in "General Data Protection Regulation (GDPR).

Name, First Name, Date and signature of researcher

Participant

International (Belgian and Australian) scientific study on how people make decisions about euthanasia involving interviews conducted over MS Teams.

I declare that I'm informed about the nature, purpose, duration, potential benefits and risks of the study and that I know what is expected of me.

I have had enough time to think and I have been able to ask all the questions that have come to mind and I have received a clear answer to my questions.

I understand that my participation in this study is voluntary and that I'm free to stop my participation in this study without having to give a reason.

I understand that during my participation personal data about me will be collected and that the research team ensures the confidentiality of these data in accordance with the relevant Belgian, European and Australian privacy legislation (Cf. AVG or GDPR)

- ☐ I agree to the processing of my personal data in accordance with the modalities described in the "Privacy and confidentiality" section.
- ☐ I consent to the processing of my data for scientific purposes.
- ☐ I consent to the publication of the research results. My name will not be published and the confidentiality of the data is guaranteed at every stage of the research.
- ☐ I consent to the sharing of my data with non-European partners (QUT).
- ☐ I consent to the storage of my data in Australia (QUT).
- ☐ I give permission to be quoted.
- ☐ I agree that my interview will be recorded with an audio and video recorder.

I agree to participate in the study described and to the processing of my personal data.
I have received a copy of the signed information and consent form.

Name, first name, date and signature of the participant