INFORMATION AND CONSENT FORM

Target audience: adult volunteers

Legal ground for the processing of personal data: consent

Language: English

SECTION 1 - INFORMATION LETTER FOR PARTICIPANTS IN RESEARCH

Title of the study: "XXX".

This is a study conducted by Ghent University in collaboration with XXX. The responsible researchers are:

XXX

Department / Faculty

Ghent University

Email: XXX

Phone no.: +XX XXX

Prof. Dr. XXX

Department / Faculty

Ghent University

Email: XXX

A. Information about the study

Dear respondent,

You are invited to participate in a study funded by Ghent University through XXX. The study focuses on XXX. Please take the time to read this information letter carefully before you decide to participate in this study. Do not hesitate to ask questions to the researcher if there are any ambiguities or if you would like additional information. You can do so by emailing XXX at XXX or by contacting them at +XX XXX. Make sure you understand everything. Once you have

decided to participate in the study you will be asked to sign the consent form as a separate attachment.

What is the purpose of the research?

This doctoral project aims at XXX

Ethical Approval

This study was given a positive advice by the Ethics Committee of the Faculty of Political and Social Sciences of Ghent University on month/day, 20XX. Under no circumstances should you consider this approval by the Ethics Committee as an inducement to participate in this study.

The study is conducted according to the guidelines in the General Ethics Protocol of the Faculty of Political and Social Sciences (Ghent University)[1]. The researcher will conduct this study in accordance with accepted standards of scientific and ethical conduct. In doing so, they adhere to the principles of research integrity as described in "The European Code of Conduct for Research Integrity" (2017, revised edition, ALLEA)[2] and adopt good research practices.

B. Information about participation

Participation in the study entails participating in XXX. Participation in this study is completely voluntary and there can be no coercion in any way. You may refuse to participate in the study, and you may withdraw from the study at any time without having to provide a reason. If you refuse to participate, or if you decide to withdraw from an ongoing study, this will in no way affect your continued relationship with the researcher nor with Ghent University.

If you wish, you can get a summary of the research findings after the study is completed and the results are known. To get a summary, you can request it from the researcher by emailing them at XXX or by phone at +XX XXX.

There is no known ongoing risk associated with this study. The study has a broader societal goal, as it is meant to advance knowledge within the field of XXX.

There will be no compensation nor reward provided when participating in this study.

C. Information about Privacy and Personal Data

The legal framework for the processing of personal data and confidential information in the context of this study is defined by:

[1] https://www.ugent.be/ps/en/resolveuid/d7b249f446514044975655213 77ea9e4
[2] https://allea.org/code-of-conduct/

- The European General Data Protection Regulation 2016/679 of April 27, 2016, in force since May 25, 2018 (the GDPR);
- The Belgian Law on the Protection of Natural Persons with regard to the Processing of Personal Data of 30 July 2018.

Researchers from Ghent University have to comply with the generic code of conduct for the processing of personal data of Ghent University[3].

What personal data are collected?

The following personal data will be processed:

- Surname and first name, occupation, gender, email address.

The following *special categories of personal* data may (exceptionally) be processed:

- Data relating ~~revealing racial or ethnic origins, political opinions, religious or philosophical beliefs~~.

Personal data will be collected using ~~audio and video recording of interviews, and audio recordings of focus groups~~.

These personal data are collected for scientific purposes related to the research but will be processed within the consent provided by the interviewee and within the safeguards imposed by the GDPR legislation and any other ethical code applicable.

For the processing of your personal data, your explicit permission will be asked. This is done by signing a 'consent form'. This consent can be withdrawn at any time by notifying the principal investigator by email (XXX).

Who has access to my (personal) data?

The research will involve, to some extent, the collection of confidential data. This means that, in order to obtain and use these data, the interviewees will be asked to provide informed consent. The informed consent will impact the degree to which such data will be used and the format in which it will be collected/preserved (i.e. degree of anonymity, possibility to record or not, taking notes during an interview etc.). The data will be stored on an external hard drive (back-up) and on the computer provided by the University.

The confidentiality and privacy of data will be safeguarded through a procedure of encryption of the sensitive data and of the consent forms signed and returned by the interviewee, specifying the procedures for the treatment of the data at stake. In addition, depending on the

[3] https://www.ugent.be/en/ghentuniv/privacy/code-of-conduct-personal-data.htm

degree of consent obtained through the form, data might also have to be anonymized and/or pseudonymized. As stated in the consent forms, only de-identified data files will be shared more broadly and archived for the longer term with a trusted data repository. No other researcher at UGent nor any external party will have direct access to the data.

Reuse of data

The research data collected in this study may also be useful in answering other research questions. Therefore, there is a possibility that the research data will be reused at a later date for other research. The reuse of the research data can be done both within the own research team and by external researchers within and outside the European Union. To this end, the research data will be made available in a controlled manner via a dedicated research data sharing platform. All necessary measures will be taken to guarantee the confidentiality of your personal data as prescribed in the UGent Generic Code of Conduct for handling personal data and confidential information.

What rights do you have as a participant with regard to the processing of your personal data?

In accordance with European and Belgian privacy legislation[4], your personal privacy is respected. As already indicated, you may withdraw your consent at any time without giving any reason. This means that your data will not be processed any further from the moment of withdrawal.

You have the right to consult the data which have been collected about you and you may also request a copy, as long as this does not violate the rights and freedoms of others, including Ghent University. Any incorrect data about you can be corrected at your request. Moreover, you have the right to be forgotten. This means that, after withdrawing your permission, you can ask to have your personal data removed.

To exercise any of the above rights, please contact the relevant researcher XXX by email (XXX) or by phone (+XX XXX).

[In the context of research, exceptions to these rights are possible, e.g., if the exercise of a right makes the achievement of the research objectives impossible or seriously impedes them. These exceptions must then be justified in the AVG register. See also https://onderzoektips.ugent.be/en/tips/00001790/ for more information.]

[4] These are: the European General Data Protection Regulation 2016/679 of April 27, 2016, in force since May 25, 2018 (this is the GDPR); the Belgian Law on the Protection of Natural Persons with regard to the Processing of Personal Data of July 30, 2018; the Belgian Law of August 22, 2002 on the Rights of the Patient.

How can I file a complaint?

If you want to file a complaint about the way your personal data are handled or if you have any questions regarding your personal data in the context of this research, you can contact the Data Protection Officer of Ghent University at privacy@ugent.be or T +32 (0)9 264 95 17.

You can also file a complaint with the Data Protection Authority, Drukpersstraat 35, 1000 Brussels (email: contact@apd-gba.be) and/or the Flemish Supervision Commission (email: contact@toezichtscommissie.be).

CONSENT FORM

Project title: "XXX".

[XXX (research groups); XXX (other organizations)]

A. Consent for participation in the research

I, the undersigned, hereby confirm that

Please check the appropriate box	yes	no
I voluntarily participate in this scientific study and give permission to the researchers to process, store, analyze and report on my data.	o	o
I have read the information sheet and have received sufficient explanation of the nature, purpose, duration, and anticipated effects of the study. I was given the opportunity to ask questions and I received satisfactory answers to all my questions.	o	o
I know that I may withdraw from the study at any time without giving a reason for this decision and without it affecting in any way my continued relationship with Ghent University, United Nations University, or the researcher.	o	o
I understand that if I discontinue my participation in this study, I can withdraw my already collected data until 5 days after the interview. A simple e-mail or phone call to the researcher will suffice. I do not need to give a reason for the withdrawal of my data.	o	o
I understand that I will receive no financial compensation for my participation in this study.	o	o
I give permission for the researcher to record the interview (audio recording and/or video recording, deleted after the completion of the research).	o	o
I wish to receive a copy of my interview transcript to verify the accuracy of the content and to provide any additional clarifications.	o	o

B. Consent for the processing of personal data

I, the undersigned, confirm that

Please check the appropriate box	**yes**	**no**
I understand that the data collected during this research will be processed in accordance with the legal provisions and the information provided to me.	o	o
I have read the information form and I know that I have rights to safeguard my privacy (including access, correction, deletion) and to whom I should turn to exercise these rights.	o	o
I give permission to the researcher to collect, process and store (personal) data from me for the purposes of this study.	o	o
I give permission to be included recognizably in publications [i.e. name, surname, professional title] as part of this study.	o	o
I hereby grant permission to the researcher to publish the research results in scientific journals and to discuss them at scientific meetings on the basis of the information that I provide, on condition that my identity cannot be traced.	o	o

C. Consent about the reuse and sharing of data

Please check the appropriate box	**yes**	**no**
(Optional) I give permission for my data to be reused for further scientific research beyond the scope of the current study.	o	o
(Optional) I give permission to share my data for further scientific research, and to do so with researchers within and outside the EEA. In doing so, all necessary measures will be taken to protect the confidentiality of my personal data.	o	o

You will receive a copy of this consent form as a participant.

Name participant	Name researcher
	XXX

Date:	Date:
Signature	Signature

Name and contact details of the researcher:

XXX, email

Ghent University – Department of XXX

Campus UFO – Technicum T1 – Floor XXX, Sint-Pietersnieuwstraat 41, 9000 Gent

XXX (other organization)

XXX (address)

Semi-Structured Interview Tool – Ethics Approval

Metric	Details
Interview duration	~~30-40 minutes~~
Number of Questions	~~Approximately 8 to 12 main questions per interviewee, with follow-ups when necessary.~~
Distribution of Questions	~~Some questions will be adapted or omitted based on the profile and expertise of the interviewee. The~~

	~~interview tool shall be considered as a standard set of questions which will be updated and modify accordingly as the research progresses.~~
Interview Format	~~Semi-structured (mixed of fixed and open-ended questions)~~
Interview Mode	~~Mainly in person and, if need be, online (e.g. Zoom, Teams).~~
Participants	XXX
Number of Participants	~~Approximately 30 to 40 individuals covering the entire project~~
Recording	Audio and/or video (if applicable)
Language	XXX
Interview Setting	~~Mixed: formal and informal.~~

Introduction (5 min)

- Researcher introduction
- Purpose of the study
- Confidentiality and consent:
    - Explain data protection measures.
    - Inform the participant of their right to withdraw any time.
    - Obtain verbal or written consent (letter and informed consent form will be shared in a timely manner before the interview).

Background and context (XX min)

Core questions (approx. XX minutes)

Critical questions

Closing and follow up (XX min)

- **Additional insights**
- **Reiterate confidentiality and the next steps**