

## **Information relating to the processing of your personal data**

This document is related to the **processing of your personal data processed in the study you just read about**. The project manager(s) will take all necessary measures to **protect the confidentiality and security of your personal data**, in accordance with the **General Data Protection Regulation (GDPR - EU 2016/679)** and the Law of 30 July 2018 on the protection of individuals with regard to the processing of personal data.

### **Who is the controller?**

The Data Controller is the promoter of the study, namely the University of Liège, whose headquarters is located at Place du 20-Août, 7, B- 4000 Liège, Belgium.

The internal investigators are the investigators whose names appear at the bottom of this document.

### **What data will be collected?**

The investigator will collect identification data (name and address email). He/She undertakes to collect only the data strictly necessary and relevant to the purposes pursued.

#### **How will the data be collected?**

They will be collected by the investigators of the study following the filling of questionnaires. A study-specific code number will be given for each participant while filling out the questionnaires online. Identification and research data will be stored in two separate databases and the information is linked to each other by means of codes. The identification document will be destroyed 7 years after the publication of the study.

#### **How long will this data be kept and by whom?**

All the data collected during this study will be associated with an identification number (pseudo-anonymisation technique) whose code is known only to the investigators and their team. These data will be kept by the promoter and his team for the time required for the collection, recording, consultation and analysis of these data as well as the time required for the writing and publication of scientific articles, and this for a maximum of 7 years. At the end of this period, the list of codes will be destroyed, and it will no longer be possible to establish a link between the coded data and yourself. If you withdraw your consent to participate in the study, in order to guarantee the validity of the search, the data coded until the moment of your interruption will be retained. No new data may be transmitted to the promoter.

### **Who will be able to access and use this data?**

Personal data can be consulted and used by the supervisor of the study and the researchers involved in this project who's names appear at the bottom of this document.

The (coded) research data may be transmitted to the Belgian or other regulatory authorities and to the relevant ethics committees.

### **Will these data be made anonymous or pseudo-anonymous?**

The investigator has a duty of confidentiality regarding the data collected. This means that they will not only never reveal your name in the context of a publication or conference but will also code your data (in the study, your identity will be replaced by an identification code) before any further processing.

The investigator and his team will therefore be the only ones able to establish a link between the data transmitted throughout the study and yourself. The personal data transmitted will not contain any association of elements that could identify you. For the research data manager designated by the sponsor, the transmitted data do not identify you. This manager is responsible for collecting the data collected by all investigators involved in the research, their treatment and their protection in accordance with the legal requirements relating to the protection of privacy.

### **For what purpose(s) will this data be collected?**

The collected data will be used for research on near-death experiences. The results of this study will be systematically anonymized before any dissemination. It may be used in:

- Publication of articles presenting the results of the study in specialized or popular journals;
- Communication of the results of the study during congresses and/or realization of any activity allowing their dissemination;
- Use of the results in university education;
- Re-use of data collected for the purpose of carrying out complementary studies in the same field of research.

### **On which legal basis will your data be collected and analysed?**

The acquisition and the use of your personal data will rely on your acceptance to fill in the questionnaire. Filling out the questionnaire will mean you accept that the personal data stated before can be used and analysed for research purposes as stated in the next paragraph.

### Will this data be transferred outside the University?

The (coded) research data may be shared with other physicians and / or organisations working with the supervisor of the study. They may also be sent to other sites of the supervisor in Belgium and other countries where the standards for the protection of personal data may be different or less restrictive. As explained above, the transmitted data will be encoded<sup>1</sup>.

### What rights do I have and how to enforce my rights?

#### My rights

As provided for in the GDPR (Art. 15 to 23), each data subject may, by proving his identity, exercise a series of rights:

- to obtain, free of charge, a copy of the personal data concerning her/him processed in the context of this study and, where appropriate, any available information on their purpose, origin and destination;
- to obtain, free of charge, the rectification of any inaccurate personal data concerning her/him and to obtain that incomplete data be completed;
- to obtain, subject to the conditions laid down by the regulations and free of charge, the deletion of personal data concerning her/him;
- to obtain, subject to the conditions provided for by the regulations and free of charge, the limitation of the processing of personal data concerning her/him;
- obtain, free of charge, the portability of the personal data concerning her/him and that he/she has provided to the University, meaning to receive, free of charge, the data in a commonly used structured format, provided that the processing is based on consent or on a contract and that it is carried out using automated processes;
- to lodge a complaint with the Data Protection Authority (<https://www.dataprotectionauthority.be/>, [contact@apd-gba.be](mailto:contact@apd-gba.be)).

#### How to enforce my rights?

To exercise these rights, you may contact the person(s) responsible for the research project mentioned in the welcome page of the questionnaire (or by email to [cmartial@uliege.be](mailto:cmartial@uliege.be)) or the University Data Protection Officer, either by e-mail ([dpo@uliege.be](mailto:dpo@uliege.be)), or by letter dated and signed at the following address:

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<sup>1</sup>The supervisor therefore will have to respect the constraints of the European directive and the Belgian legislation on the protection of privacy

Université de Liège  
Mr Data Protection Officer,  
Bât. B9 Cellule "GDPR",  
Quartier Village 3,  
Boulevard de Colonster 2,  
4000 Liège, Belgium.

***By filling out this questionnaire, I declare that I have read and understood the 4 pages of this sheet on the protection of personal information. I understand the nature and purpose of my participation in the project and have the opportunity to ask questions. To the present, I freely accept to participate in the project.***

*We declare to be responsible for the conduct of the present research projects. We undertake to respect the obligations set out in this document and also to inform you of any element that could change the nature of your consent.*

**Pr. Steven Laureys (Uliège, Belgium)**

**Dr. Charlotte Martial (Uliège, Belgium)**