**Information for the participant on the processing of personal data**

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| **Title of the study:** Co-design of an electronic diary (eDiary) application for patients withParkinson’s disease (PD)  **Acronym:** MyPD  **Sponsor of the study:** University of Luxembourg (UNILU)  **Chief Scientific and Medical Investigator of the study:**  Prof. Dr. med. Jochen KLUCKEN  Luxembourg Centre for Systems Biomedicine University of Luxembourg Campus Belval, Biotech II-Annex 6, avenue du Swing L-4367 Belvaux, Luxembourg  Email: jochen.klucken@uni.lu  Tel: +352 46 66 44 6399  **Study assistant:**  Marijus Giraitis, clinician- scientist  Contact details:  Email: marijus.giraitis@ext.uni.lu  Telephone: **+**352 621 519 122  Data protection officer  [dpo@uni.lu](mailto:dpo@uni.lu) |

# CONFIDENTIALITY AND PROTECTION OF PERSONAL DATA

As part of the study entitled MyPD, we will collect and process some of your personal data to contact you for your participation in the co-design of an application as a digital support in management of Parkinson’s disease.

University of Luxembourg is responsible for collecting, analysing and processing your personal data. The University will ensure that your data is protected, in accordance with the General Data Protection Regulation (EU) 2016/679 of 27 April 2016 **(known as the GDPR)** and all subsequent texts replacing or supplementing this Regulation, in particular, Luxembourg’s law of 1 August 2018 on the organisation of its National Commission for Data Protection and the implementation of the GDPR (collectively known as the **Law on Data Protection**).

**What type of data will we collect?** If you choose to take part in the study, we will only collect the personal data we need to achieve the scientific aims of our study.

We will collect the following data from you by means of questionnaires in paper/digital form and/or individual interviews and/or group-based discussions.

* For participants having Parkinson’s disease only: data relating to your health (clinical status, medical history – such as your symptoms, date of diagnosis etc)
* For all participants:
* personal data (age or month/year of birth, gender),
* other categories of processed data: email address and other data (your personal life (lifestyle and daily activities and help you receive for it), your level of education and profession, your socio-demographic information, your working life, your satisfaction with healthcare services, your level of self-management and health knowledge)

**On what legal basis will we process your data?** The use of your personal data is necessary to enable us to achieve the aims of the study. The study is conducted in the public interest and for the purposes of scientific research (art. 6.1e and art. 9.2j of the GDPR).

In practice, if you decide to withdraw from the study, data that has been collected until the date of your withdrawal will continue to be processed for scientific or statistical research by University of Luxembourg or other researchers, in an anonymous or pseudonymized form (study ID). From the date of your withdrawal, no further data will be collected from you.

**Who will have access to your data?**

Apart from the scientific PI and the authorised members of the clinical team working under his/her responsibility, only the following categories of persons will be able to access your data in relation to their respective duties:

Names or data that directly identifies you (first name, last name, email address):

* Authorized members of clinical study team working at the study site (involved in organizing and running study activities, as described in Ethical Information Notice.

Pseudonymised data:

* the clinical team working under the responsibility of the scientific PI

We may also need to grant access to your data to service providers carrying out work on our behalf, such as IT companies (responsible for hosting or maintenance services, for example). These organisations are bound by stringent security and confidentiality obligations, as required by the law, and the services they provide are subject to contractual agreements. Finally, in cases where particular inspections or audits need to be carried out, the competent authorities may also have access to your personal data.

Your data will not be used for any fully automated decision-making processes or for any profiling purposes.

**What are your rights?** You will have the right to access and amend your personal data. In accordance with the conditions set out by the law \*, you will also have the right to object to the way in which your data is being used, to request that your data be deleted, to ask to restrict certain aspects of the processing of your data. You will not be able to request that your data be deleted in certain cases – if data is already used for analysis or after the deletion of the table of correspondence 2 years following the end of the study. If you wish to exercise your rights, you should contact the scientific PI or his designated representative.

Lastly, you have the right to lodge a complaint with Luxembourg’s National Commission for Data Protection (CNPD) in relation to the processing of your personal data.

For information about how the University of Luxembourg processes your personal data, please contact the University of Luxembourg Data Protection Officer by email at dpo@uni.lu or by post at the following address:

UNIVERSITY OF LUXEMBOURG

Chargée de la Protection des données.

2 Av. de l'Université, 4365 Esch-sur-Alzette

LUXEMBOURG

\*The University of Luxembourg will examine all your requests to exercise rights in accordance with the GDPR and the Luxembourg law of August 1, 2018 on the organisation of its National Commission for Data Protection and the implementation of the GDPR. As a result of this assessment and to the extent that we put in place appropriate measures with regard to the protection of your data, we may have to refuse your request if the fulfilment of your request makes impossible or seriously hinders the achievement of the scientific purposes of our study. We will inform you of our decision within one month upon receipt of your request This delay may be extended by a further two months under exceptional circumstances, such as if the request is complex. In this case, the University shall inform the data subject within one month of receiving the request, explaining the reasons for the delay. If University of Luxembourg decides not to grant your request, you have the possibility to contest our decision with the CNPD.

**How do we protect your personal data?** The University of Luxembourg takes appropriate security measures, based on the sensitivity of the information concerned, to protect your data from the risk of unauthorised access, loss, fraudulent use, disclosure, modification and destruction. Your data will be treated as strictly confidential. It will also be pseudonymised, meaning that your name will be replaced by a unique study ID. This study ID will not directly identify you and will only be used to process your data for scientific purposes. Your identity will never be disclosed in any document produced for the public or for other institutions. The correspondence table showing the link between your name and the study ID will be kept confidential and secure by the study investigator and will be stored separately from the other data associated with the study. Only a small number of people will have access to it (see “Who will have access to your data?” above).

**For how long will your data be stored?**

Your data will be stored, in accordance with the applicable legal provisions. The correspondence table between the participants’ personal data and the study ID (pseudonyms) will be deleted 2 years after the end of the data collection in the study. UNILU will retain the data collected via the online survey, individual interviews and focus groups in a pseudonymized form for 2 years, followed by additional 8 years in an anonymized form for a total retention period of 10 years following the end of the study. Data will be stored within the UNILU secured databases. Audio recordings from the interviews and focus groups will be deleted from the local file one month after transcription performance. Emails collected from people contacting us directly will be deleted 6 months after the first contact in case the person does not participate in the study.

**Transfers of data outside the European Union.**

None of your personal data will be transferred outside the European Union.

For more detailed information on the appropriate measures taken by the University of Luxembourg, please send your request by email to the University of Luxembourg Data Protection Officer at [dpo@uni.lu](mailto:dpo@uni.lu).