**Partial GDPR form of University of Luxembourg**

Full version of this document is available on DPO intranet or via ServiceNow.

# Step 1 – Description of project and associated processing activities

## General information about the processing

|  |  |
| --- | --- |
| Project/Study/Service **Title** |  |
| Project/Study/Service **Acronym**  (Internal reference) |  |
| Umbrella project name (if applicable) |  |
| Project/Study/Service **Applicant/Principal Investigator** from University |  |
| University department(s)/entity’s department (e.g LCSB, C2DH, SnT, FHSE, FTSM, FDEF) |  |
| Data manager (if applicable) |  |
| IT developer (if applicable) |  |
| Other contact names from University/entities involved in the project/service | *Name and department/unit* |
| Cohort name (if applicable)  New cohort or existing cohort? |  |
| Category of Data subjects | *Adults between X and Y years old* *Patients with a disease* *Healthy control (volunteers)* *Minors* *Students* |
| Start project Date |  |
| Expected end Date |  |
| Retention period |  |

*Instructions are in Red and italic*

*Examples are in Grey and italic*

## Context: scope/characteristics of the Project/Study/Service

*(10 to 15 lines max.):*

Purpose(s)/objective(s)

* *Research area*
* *Study/Service goals*

Funding sources

* *Funding bodies, grant reference number, …*

*Horizon 2020 (121004982-1)*

Time frame of the study/project (recruitment period, ...)

* *Overall time frame of* ***collection of the data****. Describe the time frame even if the data collection is not performed by the University or the data collection was already performed in the past.*

*e.g Data or the cohort was collected during 2013-2015 by clinical partners.*

Participants/patients (in Luxembourg and other countries if you know)

* *Describe the criteria for inclusion/onboarding of the subjects (age range, geographical location, disease, etc.).*
* *Include number of data subjects. If not known, provide an estimation.*

*e.g Participants will be selected from among the residents of Luxembourg through AICH panelists. Initial phase of the study counts with 150 participants (minimum).*

Number of variables processed (e.g: how many entries are in the data dictionary)

* *In case the exact number is not known, provide an estimate.*

*Data dictionary contains approximately 400-500 variables. Around 120 variables are collected for all participants (mandatory).*

Qualified personnel with access to the data

* *List of people or groups affiliated to University or external people accessing the data under University instructions*

*e.g Research team (or a limited number of persons within the team), research collaborators, medical doctor, psychologist, historian, …*

e.g Qualified personnel interacting with/recruiting/contacting the data subjects (if applicable)

* *Describe people/institution in direct contact with data subjects (it can be also responsibility of the partner institution)*

*All clinical partners are reponsible for contact with the data subjects.*   
*All team members with shared University affiliation.*  
*Clinicians are responsible for recruitment. Medical coaches (UNI employees) interact in regular intervals through visits.*

* *Provide information if data are directly identifying, pseudonymised or anonymised? If pseudonymised, have you thought about anonymising your data (why it was not an option)?*

*Data is pseudonymised by/following standard de-identification procedure (ref)*

*Directly identifying data are kept separate from the research data / are kept by project partner.*

*Data cannot be fully anonymised due to its nature (genetic data).*   
*Data will be fully anonymised after X years as described in …*

### Identify the role of the University(including entity) under the GDPR

|  |  |  |
| --- | --- | --- |
| **Role** | **Definition** | **Tick the right role** |
| Controller | The University determines **alone** the purposes and means of processing personal data. |  |
| Joint-Controller**\*** | The University determines **with other Parties** the purposes and means of processing personal data. |  |
| Processor | The University is responsible for processing personal data on behalf of a Controller (as per the Controller’s instructions and for the Controller’s purpose). |  |

**\* For the activities performed as Joint-Controller,** you confirm that:

* You have a **common/complementary objective** regarding the whole project or a specific data processing activity within the project

Yes  No

* You have **jointly designed** the project or part(s) of it (e.g. you have jointly decided who are the data subjects, which categories of data are processed, how data will be stored, accessed or handled, with whom data will be shared, which security measures should be followed, etc.)

Yes  No

* The other party(ies) **take(s)** strategic **decisions** with you

Yes  No

* Together with you, the other party(ies) has/have **decisive influence** over whether and how the data processing takes place (the table below lists several categories of data processing)

Yes  No

**Filling the form for training assessment is voluntary behind this point.**

|  |  |  |  |
| --- | --- | --- | --- |
| **Data Processing activities (categories)** | The University | Collaborator | UNI and Collaborator(s) |
| Collection of Data and/or samples |  |  |  |
| Provision of existing data/samples (e.g.: cohort provider) |  |  |  |
| Pseudonymisation |  |  |  |
| Data storage |  |  |  |
| Data curation |  |  |  |
| Data analysis |  |  |  |
| Generation of data (from sample processing, inferred from the collected data …) |  |  |  |
| Data computing services |  |  |  |
| Data sharing |  |  |  |

### Is Ministry of Health and CNER submission required?

Does your project/study focus on humans (data, samples, surveys, …)? .……. Yes/No

Does your project/study contribute to the development of scientific or medical knowledge?......Yes/No

Will subjects’ recruitment take place specifically during your project/service?.………Yes/No

*Instruction:* ***If ‘Yes’ is ticked for all questions*** *the Ministry (and indirectly CNER) submission must be prepared. Please note that the latest version of the Informed consent form and Information sheet are available on DPO Intranet(only these validated documents have to be used, no other former template).. For LCSB & FSTM involving biomedical research contract directly the Data Protection Office.*

## Description of processing activities in relation to your project/study/service

### Processing activities

*Instruction: Briefly describe (****step by step****) all processing activities involving personal data that you will perform within the course of this project/study/service (add lines as needed).*

*When the University acts as a Data Processor (not as a Data Controller), please only list/details the processing activities for which the University is responsible.*

| **Entity**  *(LCSB, SnT, C2DH, FSTM, FDEF, FHSE or any other partner, client,…)* | **Investigator or contact name** | **Country/**  **location** | **Short description of processing activity** | **Role**  C – Controller  J – Joint-Contr.  P – Processor | | |
| --- | --- | --- | --- | --- | --- | --- |
| **C** | **J** | **P** |
| *CHL* | *Dr. X* | *Lux.* | *Recruitment of patients with Gastro-intestinal disease.* | X |  |  |
| *Consent administration (distribution, collect and storage)* | X |  |  |
| *Blood draw for standard of care’s analysis done by CHL nurse (blood samples are not transferred to the University). 4 draws will be performed.*  *Send results of the patients’ blood analysis (included in the standard of care) to LCSB.* | X |  |  |
| *Collection of biopsy tissue (once) during the surgery.* | X |  |  |
| *LCSB* | *Bioinformatics Core* | *Lux.* | *Data Storage* |  |  | *X* |
| *Data Pseudonymization* |  | *X* |  |
| *Data curation* |  | *X* |  |
| *Data transfer to other research sites* |  |  | *X* |
| *Data destruction* |  |  | *X* |
| *LIH* | *Group leader* | *Lux.* | *eCRF administration, data Management and statistical analysis,* |  | X |  |
| *Collection of Data and/or samples* |  | X |  |
| *Provision of existing data/samples (e.g.: cohort provider)* |  | X |  |
| *Pseudonymisation* |  | X |  |
| *Data analysis* |  | X |  |
| *Generation of data (from sample processing, inferred from the collected data …)* |  | X |  |
| *Data computing services* |  | X |  |
| *Data sharing* |  |  | X |

Data disclosure **(recipients of personal data)** means any person to whom the data are disclosedbut who has not already been identified as processor, controller or joint-controller

| **Name** | **Country** | **Purpose of the transfer** | **Data transfered** | **Transfer technology or method** | **Specific security measures** |
| --- | --- | --- | --- | --- | --- |
| *Journal’ editor (when pseudomimyzed raw data are provided)* |  | *Publication* | *Aggregated data or raw data* | *Online submission platform* | *Second pseudonymisation* |
| Insurance companies |  | In case of occurrence of event insured, data/information on the volunteer and the accident/insured event has to be transferred from UNI to the Insurance company | data/information on the volunteer and the accident/insured event | Filesender | Communication will be limited between the University competent service and the insurance company to guarantee for confidentiality |

### Pseudonymisation method and samples coding (if applicable)

*Describe (text or figures) the pseudonymisation steps and the samples coding by taking into consideration all the systems (pseudonym for each software? Code for each sample type?). Explain when the codes are created, how are they linked together…*

## Categories of personal data

Remove rows which do not apply

| **Categories**  **of personal data** | **Data source/origin** | **What are the personal data**  **used in your project/study/service?** |
| --- | --- | --- |
| **Stand**a**rd personal data** | | |
| Basic personal identification data | *Direct paper questionnaire* | *gender, marital status,* |
| *Direct electronic questionnaire (web browser, mobile application…)* | *gender* |
| *Indirect via medical records…* | *Name, family name, birthday (age)* |
| Other identification data |  | *Social security N°, nationality, ID accreditation documents (ID card, passport, driving license, visas, permits, etc.), living habits (not related to health) etc…* |
| Data conveying information about civil status |  | *Family composition, birth/death certificates, civil status, birth location****,*** |
| Contact details |  | *Private phone, email, address* |
| Professional data |  | *Professional phone, e-mail, address, employee number, function, grade, coefficient,**educational qualifications, professional training, employers (past and present), profession, specialisation, skills, annual reviews* |
| Location data |  | *Travel itinerary, address of the hotel during travel, place of residence, GPS data, GSM data*  **For Geolocation data (describe)**:  - Frequency of, and the level of detail of, geolocation data (ie: information on a relevant territorial zone):  - Is it intended to follow participants’ movements:  - Provide accurate information on the purpose of such processing (e.g. is geolocation history stored? If so, what is its purpose?):  - Specify if geolocation is only activated when the participant launches a functionality that requires his/her location to be known, and by default (or not) and continuously when the app is started (or as appropriate);  - Specify if geolocation is deactivated automatically (under which process) or can be deactivated at any time. |
| Traffic/Connection data |  | *IP address, event logs, telephone consumption, history of consulted website, history of download,* |
| Economic and financial data (individuals) |  | *Credit card number, bank account details, income, tax situation, salary, bonus, benefits in kind, expenses…* |
| Pictures & sounds |  | *Videos, Photographs, Recordings…* |
| **Sensitive Category of personal data** | | |
| Health data |  | *Medical certificates, diseases, diagnostics reports, health metrics, dietary habits, health economics data, clinical history, pre-analytical data (sample annotation)...* |
| Genetic data |  | *Genetic profiles, any other genetic data (genetic test results), DNA samples* |
| Biometric data (where used for ID purposes) |  | *such as fingerprints or facial recognition, biometric data related to health* |
| Political opinions |  | *Such as your opinion about politics, the adhesion to a public party* |
| Data conveying information about origin |  | *Race, ethnicity* |
| Sex life / Sexual orientation |  |  |
| Data conveying information about personal beliefs /opinion |  | *Religious, philosophical beliefs, political inclinations, trade-union membership etc…* |
| Behavioural data |  | *Profiles based on food, leisure, shopping preferences and habits* |
| Criminal data |  | *Criminal convictions, offences, including suspicion of those* |
| Trade union membership |  |  |

### Data minimization

*Please describe data minimization efforts in the project.*

## Data and Samples flow between the different partners

***Please highlight the physical separation of the databases/dataset and all the information systems used***

* *Find an example below to show you what is expected: highlight all the parties involved (or categories of parties if the personal data processing activities are the same), the information systems used by each party…*

This is a place for data flow diagram, covered in the 1st day of ELIXIR DMDS training.

Provide any other relevant comments: