DATA PROTECTION IN THE CONTEXT OF THE HELICON PROJECT

This document aims to inform you about the linking and the use of pseudonymised data in the context of the HELICON project, a project of Sciensano and ULB that aims to unravel the social inequalities and the long-term and indirect health effects of the COVID-19 crisis in Belgium. More information about the project is available via www.brain-helicon.be.

This message concerns all Belgian citizens, and in particular:

- All persons tested because of a suspicion of COVID-19 in Belgium.
- All persons hospitalized because of a suspicion of COVID-19 in Belgium.

Why the HELICON project?

The spread of the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) and the resulting outbreak of the disease COVID-19 has faced Belgium and most other countries worldwide with unprecedented challenges. During the crisis, active surveillance systems have been put in place to monitor in real-time the number of cases, hospitalizations and deaths. The COVID-19 crisis however has a multidimensional impact on population health, occurring at different time scales and affecting different populations.

Despite the wealth of information on the current, immediate impact of COVID-19, several knowledge gaps remain on the other dimensions of the COVID-19 crisis impact:

1. What is the social patterning of COVID-19 testing, infection, hospitalizations and mortality?
2. What is the medium- and long-term direct health impact of COVID-19 infections?

How will this project take place?

To answer these research questions, Sciensano, in collaboration with ULB, launched the HELICON project. For the purpose of this project, no new data are collected, but existing databases are linked. All necessary data for this project are indeed already part of existing databases.

It is crucial to note here that only pseudonymised data will be linked based on a code. This means that the involved researchers will not be able to identify you. Your name, national register number, date of birth and address are not available to the researchers. Only data necessary for this project will be used from the existing databases.

The following data will be used from the, already existing, databases mentioned below:

- **HealthData COVID-19 database (or Database II Contacttracing)**: demographical data (sex, age, postal code) of all persons who had a COVID-19 test done in Belgium, data clarifying the reason for this test, and test results.
- **HealthData COVID-19 Clinic Database**: demographical data (sex, age, postal code) and clinical data (such as information on medical examinations, treatment, complications, hospital stay, ...) of all persons hospitalized with a confirmed COVID-19 infection in Belgium.
- **Statbel**: demographic data (such as migration background, household status) and socio-economic data (such as level of education, employment status, income level) of

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a random selection of all Belgian citizens and the individuals included in the COVID-19 contact tracing and clinic databases.
- **Database of the Intermutualistic Agency (IMA)**: data on healthcare use and reimbursement status of a random selection of all Belgian citizens and the individuals included in the COVID-19 contact tracing and clinic databases.

The registration of data in each of the above mentioned databases has been previously approved by the competent authorities.

Who is responsible for the processing of the data?

Sciensano and ULB are responsible for the processing of the data. The processing is based on the grounds of public interest (art. 6.1 (e) of the General Data Protection Regulation (GDPR)) and in particular for data concerning health, for reasons of scientific research (art. 9.2 (j), of the GDPR).

Concerning the legal framework of the data processing, we refer you to the

- Articles 3 § 1 4° and Art. 10 § 3 of the Samenwerkingsakkoord van 25 augustus 2020 tussen de Federale staat, de Vlaamse Gemeenschap, het Waalse Gewest, de Duitstalige Gemeenschap en de Gemeenschappelijke Gemeenschapscommissie, betreffende de gezamenlijke gegevensverwerking door Sciensano en de door de bevoegde gefedereerde entiteiten of door de bevoegde agentschappen aangeduide contactcentra, gezondheidsinspecties en mobiele teams in het kader van een contactonderzoek bij personen die (vermoedelijk) met het coronavirus COVID-19 besmet zijn op basis van een gegevensbank bij Sciensano / Accord de coopération du 25 août 2020 entre l'État fédéral, la Communauté flamande, la Région wallonne, la Communauté germanophone et la Commission communautaire commune, concernant le traitement conjoint de données par Sciensano et les centres de contact désignés par les entités fédérées compétentes ou par les agences compétentes, par les services d'inspections d'hygiène et par les équipes mobiles dans le cadre d'un suivi des contacts auprès des personnes (présumées) infectées par le coronavirus COVID-19 se fondant sur une base de données auprès de Sciensano (only available in French and Dutch).
- Article 4 of the Wet van 25 februari 2018 tot oprichting van Sciensano / 25 FEVRIER 2018. – Loi de 25 février 20218 portant création de Sciensano (only available in French and Dutch).

The processing of data is done by authorized persons, under supervision of a medical doctor of Sciensano (Dr. Karin De Ridder). The processing is technically supported by the HealthData platform.

Who has access to these data?

The involved researchers at Sciensano and ULB have access to the linked pseudonymised data.

Sciensano and ULB can share anonymous or pseudonymised data with other scientists in the framework of national, European and international collaborations. Where applicable, such reuse will require approval from the Information Security Committee. The persons/institutions with whom information will be shared, will also not be able to identify you.

Reports and scientific publications with the results of the HELICON project will be made public and will be shared with partners and federal and regional ministries of public health. These reports will only contain aggregated data (in text, tables and graphs), so once again you will not be identifiable.

How long will the data be stored?

The pseudonymised data will be stored 10 years, in accordance with the approval request to the Information Security Committee.

What are your rights?

The General Data Protection Regulation (GDPR) gives persons whose data are processed a right of access, rectification, deletion, restriction and objection. Sciensano and ULB will only be able to respond to such requests if it is possible to link the data to the requesting individual. Since this project links pseudonymised data, it is not possible to know which data belongs to which person, and Sciensano and ULB would therefore need additional information from the applicant.

The project is requesting the approval of the Information Security Committee to use these personal and medical data within a clearly defined framework.

If you believe your rights have been violated, you can file a complaint with the Data Protection Authority (www.dataprotectionauthority.be).

More information?

For more information regarding the processing of your data, please contact the Data protection Officer of Sciensano: dpo@sciensano.be.

For more information regarding the functioning and services of Sciensano, please visit our website: www.sciensano.be.

For more information regarding the functioning and the services of Health Data, please visit: www.healthdata.be.