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LE GOUVERNEMENT
DU GRAND-DUCHÉ DE LUXEMBOURG
Ministère de la Santé

Direction de la santé

YOUNG50

Data protection notice Participant



LUXEMBOURG
INSTITUTE
OF HEALTH



Information for the participant on the processing of personal data

Title of the study: Stay Healthy-Cardiovascular Risk Prevention-Young50

Acronym: YOUNG50

Funded by : European union and Directorate of Health / Ministry of health Luxembourg

Project coordination: Directorate of Health and Luxembourg Institute of Health

Project leader of the study: Marie LOUYOT

Medical Investigator of the study: Dr Sophie COUFFIGNAL

Contact details:

Public Health Expertise, Department of Precision Health, Luxembourg Institute of Health

Telephone: +352 26970-747 (MON-FRI, 9 AM – 1 PM)

E-mail: young50@lih.lu

PROTECTION OF PERSONAL DATA

As part of the study entitled YOUNG50, we will need to collect and process some of your personal data to meet the scientific objectives of the study. The collection of all data is mandatory for you to participate in the study.

The Luxembourg Institute of Health (LIH) and the Luxembourg Directorate of Health (DiSa) are jointly responsible for collecting and processing your personal data in compliance with the General Data Protection Regulation (EU) 2016/679 of 27 April 2016 (**known as the GDPR**) and as well as with the 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 have been collected? We collected the following personal data from your general practitioner: family name, first name, sex, year of birth, address. These data are collected in order to send you an invitation to participate in the study and to confirm your eligibility for the study.

What type of data will be collected? 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. The questionnaire used is a standardised questionnaire made by the European Union project.

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We will collect the following data from electronic questionnaires, blood test results and clinical assessment by your GP (General Practitioner):

- health information: weight, height, waist circumference, blood sugar, cholesterol, blood pressure, menopause status (for women), treatments, medical history
- other categories of processed data: sex, lifestyle and eating habits, alcohol/tobacco consumption, education, occupation, type of cohabitation..
- satisfaction opinions about the study

We will collect the following data by phone to schedule your appointment:

- phone number and appointment date.

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, which LIH is conducting in the public interest and for the purposes of scientific research (art. 6.1e and art. 9.2j of the GDPR) and Ministry of Health for reasons of public interest in the field of public health (art. 6.1e and art. 9.2i of the GDPR and amended law of 21 November 1980 on the organization of the "Direction de la Santé" - article 1 paragraph 8).

Who will have access to your data?

Only the following people will have access to your data in relation to their respective duties:

Information that directly identifies you (first name, last name, address, telephone number, etc.):

- Medical Investigator of the study and the administrative assistant at the Public Health Expertise unit (PHE, LIH) which will have access to the Study's correspondence table, linking your identity data to the code assigned to you for the study
- Your GP will have access to a report of your answers to the questionnaire

Coded (pseudonymised) data:

- the project leader of the study at the LIH and the team working under her responsibility,

Aggregated (anonymized) data:

- the project leader of the study at the LIH and the team working under her responsibility,
- the Directorate of Health
- European project team for the final report of the study

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 be used for a profiling process needed to evaluate your cardiovascular diseases risk in this study. It will be used in order to give you the more suitable recommendations from your GP. Under no circumstances will this profiling be used in order to take decisions concerning you or for analysing or predicting your personal preferences, behaviours and attitudes.

What are your rights?

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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 and to ask to restrict certain aspects of the processing of your data. If you wish to exercise your rights, you should contact the LIH's Data Protection Officer by email at dpo@lih.lu or by post at the following address:

LUXEMBOURG INSTITUTE OF HEALTH
Protection des données
1A-B, rue Thomas Edison
L-1445 Strassen
LUXEMBOURG

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.

How do we protect your personal data?

The LIH 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 confidential reference code. This code 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 reference code will be kept confidential and secure by the Medical Investigator and administrative assistant 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?

If you agree to participate in the study, your pseudonymised data will be stored, in accordance with the applicable legal provisions, for a period of 2 years following the end of the data collection. Your contact details will be destroyed two months after the end of the study.

If you refuse to participate in the study, your contact details will be destroyed two months after the end of the recruitment period of 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 LIH, please send your request by email to the LIH's Data Protection Officer at dpo@lih.lu.

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