

# CARDIOCARE - Privacy Notice

Version v1.0



**Last Updated: July 1<sup>st</sup>, 2021**

This document was drafted pursuant to art. 13 of the EU General Data Protection Regulation 2016/679 (hereafter: "GDPR") in order to let you know our privacy policy and to understand how your personal data is being handled for the scientific research purposes of the CARDIOCARE project (hereinafter "Project"). The general information published on this page is intended to supplement the information that has been given to data subjects (for example on a participant information sheet or a consent form) when collecting their personal data to allow them to exercise their rights.

## 1. Purposes of the processing

CARDIOCARE has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No 945175, entitled: "AN INTERDISCIPLINARY APPROACH FOR THE MANAGEMENT OF THE ELDERLY MULTIMORBID PATIENT WITH BREAST CANCER THERAPY INDUCED CARDIAC TOXICITY". The Project is a collaborative effort from leading scientists in 7 countries across Europe (Greece, Italy, Cyprus, Slovenia, Sweden, Netherlands, and France). CARDIOCARE is aiming to improve the monitoring, treatment and overall care provided to the **elderly breast cancer patients** which are at high risk of developing cardiac toxicity from cancer therapy.

More specifically, aged-related factors and co-morbidities increase elderly breast cancer patients' vulnerability to cardiotoxicity due to cancer treatment. CARDIOCARE will focus on the elderly breast cancer population and through a holistic approach including mobile Health applications, wearable sensors and biomarkers, will provide the ability to patients to take part in their care process and enhance their physical and mental health, contributing to an individualized care plan and a psychological adaptation to their disease. CARDIOCARE will enable the development of an effective risk stratification model in mitigating cardiotoxicity and adverse events, minimizing hospitalisations and enhancing quality of life.

## 2. About the Data Controller

The organisation which is collecting and processing your personal data, is the

- ONKOLOSKI INSTITUT LJUBLJANA (IOL), established in ZALOSKA CESTA 2, LJUBLJANA 1000, Slovenia.

For the scientific research purposes of the project, IOL (hereinafter "Data Provider") will provide **non-identifiable data (pseudonymised data)** to other CARDIOCARE research partners, all acting as Joint Controllers.

If you have any questions about the particular research study you are participating in, please use any contact details you have already been supplied with or feel free to contact us at the following email addresses: [bseruga@onko-i.si](mailto:bseruga@onko-i.si), [dribnikar@onko-i.si](mailto:dribnikar@onko-i.si)

For any information concerning the processing of your personal data by UOI, you can contact the Data Protection Officer at the following email address: [tdzambasovic@onko-i.si](mailto:tdzambasovic@onko-i.si)

## 3. About the personal data we process

For the medical research purposes of CARDIOCARE, IOL will process:

- (i) Newly collected data from patients enrolled in the CARDIOCARE prospective clinical study

The types of personal data that shall be processed for the purposes of the project include clinical data, cardiac imaging, serum biomarkers, multi-omics (genomics, epigenomics, metagenomics) data, Quality of Life data and intrinsic (mental and physical) capacity monitoring data including wearable sensor and mobile Health application data.

The types of processing activities planned for the project include clinical, biochemical, molecular biology, biomedical imaging, machine learning and statistical modelling approaches together with wearable sensor and mHealth applications technologies involving cloud services and information security technologies. Such data processing involves also 'Profiling' of patients with automated processing of personal data in order to monitor aspects of patients' health, behaviour, location and movements. However, such 'Profiling' DOES NOT involve automated individual decision-making, with legal or similarly significant effects for the patients.

#### **4. Legal basis for the processing**

- (i) For the purposes of processing newly collected data from patients enrolled to the CARDIOCARE prospective clinical study, lawful processing is based on the following legal grounds:
  - a. Lawful Processing is necessary for the performance of a task carried out in the public interest according to Article 6(1e) of the GDPR. The task or function has a clear basis in law in line with Recital 45 of the GDPR. For non-public bodies, processing is necessary for the legitimate interests in scientific research pursued by the beneficiaries according to Article 6(1f) of the GDPR.
  - b. Additional condition for processing sensitive / special category data including health data is that processing is necessary for scientific research purposes in the public interest and in the area of public health according to Article 9(2j) and Recitals 52, 53 and 159 with appropriate safeguards in line with Article 89(1) and Recitals 156 and 157 of the GDPR.

You are not legally or contractually obliged to supply us with your personal information for research purposes.

#### **5. Data subject rights**

Various rights under GDPR, including the right to access personal information that is held about you, are qualified or do not apply when personal data is processed solely in a scientific research context. This is because fulfilling them might adversely affect the integrity of, and the public benefits arising from the clinical research study. For this reason,

- (i) As far as the processing of newly collected data from patients enrolled to the CARDIOCARE prospective clinical study, based on the legal grounds described above, the Data Subjects are entitled to the following rights:
  - a. The right to be informed, the right of access and the right to rectification. Based on the specific legal grounds for processing, the rights to erasure, to data portability, and to object are NOT available in line with Recital 65 and Article 17(3d), Recital 68, and Article 21(6) plus Recital 159 of the GDPR respectively.

#### **6. The recipients of the pseudonymized data**

For the scientific research purposes of the CARDIOCARE project, IOL (Data Provider) will share pseudonymized personal data to the following European Economic Area (EEA)-based Data Recipients, acting as Joint Data Controllers:

- ISTITUTO EUROPEO DI ONCOLOGIA SRL (IEO), established in Via Filodrammatici 10, MILANO 20121, Italy.
- OGKOLOGIKO KENTRO TRAPEZAS KYPROU (BOCOC), established in LEOFOROS AKROPOLEOS 32, STROVOLOS 2006, Cyprus.
- IDRYMA TECHNOLOGIAS KAI EREVNAS (FORTH), established in N PLASTIRA STR 100, IRAKLEIO 70013, Greece.
- PHILIPS ELECTRONICS NEDERLAND BV (PHILIPS), established in HIGH TECH CAMPUS 52, EINDHOVEN 5656 AG, Netherlands.
- KAROLINSKA UNIVERSITY HOSPITAL (KSBC), established in HANTVERKARGATAN 45, STOCKHOLM 104 22, Sweden.
- STREMBLE VENTURES LTD (STREMBLE), established in KO 8 GERMASOGEIA, LIMASSOL 4045, Cyprus.
- ONKOLOSKI INSTITUT LJUBLJANA (IOL), established in ZALOSKA CESTA 2, LJUBLJANA 1000, Slovenia.
- ETHNIKO KAI KAPODISTRIAKO PANEPISTIMIO ATHINON (NKUA), established in 6 CHRISTOU LADA STR, ATHINA 10561, Greece.
- ELLINIKO MESOGEIAKO PANEPISTIMIO (HMU), established in ESTAVROMENOS, HERAKLION 71004, Greece.

in order to carry out the tasks described under EU Grant Agreement No 945175.

The Personal Data shall be transferred using a Private Cloud infrastructure provided by FORTH, a CARDIOCARE partner acting as a Data Recipient and Joint Controller.

## **7. Data retention**

The Data Provider will retain the personal data as long as needed for scientific research purposes in line with Article 5(1e) and in accordance with Article 89(1) of the GDPR subject to appropriate technical and organizational measures to safeguard the rights and freedoms of the data subjects.

At the end of the project (for a minimum of 4 years, unless an extension is granted by the European Commission) and at the choice of the Data Provider, the Data Recipients shall return or destroy all the Personal Data transferred.

## **8. Right to lodge a complaint**

If you believe that the processing of your personal data is not performed in a GDPR compliant manner, you are always entitled to lodge a complaint to the Supervisory Authority at <https://www.ip-rs.si/>.

## **9. Changes made to this webpage.**

This webpage was last updated on July 1<sup>st</sup>, 2021. It is reviewed when necessary and at least annually. Any changes will be published here.