

PRIVACY STATEMENT
BELGIAN CANCER REGISTRY

Belgian Cancer Registry



CONTENTS

1. Introduction	3
2. Why does the Belgian Cancer Registry process personal data?	4
2.1 What does 'processing' personal data actually mean?	4
2.2 Which personal data does the Belgian Cancer Registry process?	4
2.3 Why does the Belgian Cancer Registry process health data?	6
Standard registration	6
Early detection of cancer	6
2.4 Security	7
2.5 Storage	7
3. Sharing personal data	8
4. Your rights	9
Individual rights	9
Data PROtection Authority	9
5. Website and cookies	10
Use of the collected data	10
Detailed information about the processing of personal data	10
6. About this Privacy Statement	10
7. Updates	10

1. INTRODUCTION

The Belgian Cancer Registry is a Public Utility Foundation, based at Koningsstraat 215 box 7, 1210 Brussels, and represented by a Medical-Director. When carrying out its activities the Foundation is bound by the Coordinated Act on the exercise of health care professions of 10 May 2015, which establishes the modalities for the cancer registry in detail.

Our legal task is to collect data on cancer, subject it to quality control, process and analyse it, encrypt and store it, report on it, make it accessible for research and protect it. It is a legal requirement to register new cancer diagnoses with us, whether or not discussed at a MOC (Multidisciplinary Oncological Consultation). In addition, the Belgian Cancer Registry is creating a central cyto-histopathological registry, for which we collect certain test results in relation to the early detection of breast, colorectal and cervical cancer.

In order to be able to execute these tasks, The Belgian Cancer Registry may process your personal data, either as a patient or as a healthcare worker. As a *controller* (i.e., processing responsible) The Belgian Cancer Registry attaches great importance to privacy and the protection of personal data. The protection of personal data we process is a crucial aspect of our daily operations. The aim of this Statement is for us to communicate in an accessible and comprehensible manner on how the Belgian Cancer Registry handles personal data. A Data Protection Officer (DPO) has been appointed at the Belgian Cancer Registry. The DPO team can be reached via the following e-mail address:

dpo@kankerregister.org

For more information about this statement or other privacy-related questions, we invite you to contact the DPO-team.

2. WHY DOES THE BELGIAN CANCER REGISTRY PROCESS PERSONAL DATA?

2.1 WHAT DOES 'PROCESSING' PERSONAL DATA ACTUALLY MEAN?

When the Cancer Registry receives registrations and/or examines, stores, or analyses information about cancer diagnoses or the early detection of cancer, we are 'processing personal data'. 'Processing' is a broad term and refers to the various activities that Belgian Cancer Registry carries out on personal data. This includes collecting, organising, storing, updating or modifying, retrieving, consulting, using, making available, aligning or combining, deleting or destroying personal data.

2.2 WHICH PERSONAL DATA DOES THE BELGIAN CANCER REGISTRY PROCESS?

By 'personal data' we mean all information relating to an identified or identifiable individual (the 'data subject'). This may include name, address, contact details, but also information about a person's state of health, such as information communicated in the registration of a cancer diagnosis. An individual is directly identifiable on the basis of data such as name, address details, or Social Security number. Every information associated with a name therefore qualifies as personal data, because it is information about an identified person. Data can also be personal data if the individual can be identified indirectly. This is the case when it is still possible to find out to whom the personal data is relating, even if, for example, there is no name that directly designates the individual.

The Belgian Cancer Registry processes different types of personal data. Sometimes the data is received directly from the individual, sometimes we receive data from government institutions, in other cases, the data is part of a registration performed, for example, by a hospital, which sends the data to The Belgian Cancer Registry.

The Belgian Cancer Registry collects the following data:

- Healthcare workers: when you register patient data or when you are involved in the MOC for a patient, the Belgian Cancer Registry will collect your name and NIHDI number (and for healthcare workers who are performing the registration, we will also collect the name of the hospital where you work and your signature). This data collection is performed in the context of the registration which you are legally obliged to make or to which you have contractually committed. The Belgian Cancer Registry uses these data to provide you feedback regarding the registered data. The Belgian Cancer Registry will also process your NIHDI number in case of an early detection of cancer, more specifically when you ordered a lab test for which the results have to be sent to The Belgian Cancer Registry or if you are the GMR (Global Medical Record) physician for one or more patients who are part of the target population for one of the early detection of cancer programs;
- Employees from other organisations: in the context of collaboration or communication with other organisations, The Belgian Cancer Registry may use and store your professional contact information as an employee of such an organisation. This only includes contact information which is publicly available or which was provided to us by either you or your organisation. The Belgian Cancer Registry has a justified interest to process these data.
- Website users: see part 5 of this privacy statement.

The Belgian Cancer Registry also collects the following (health) data from (cancer) patients or persons who are invited to take part in one of the early detection of cancer programs:

- Unique patient identifier (name or INSZ or unique number), including demographic parameters (date of birth, sex, postal code) and, if applicable, an unique identifier for the physician, the care program and the hospital and/or the laboratory;
- Laboratory results from early detection cancer programs.
- Diagnosis according to international classification, including the date of diagnosis;
- Tumour stage (cTNM);
- Conclusion of the pathological report (including pTNM);
- Treatment with reference to guidelines or justification of deviation (including Omnio-status for breast cancer screening);
- Follow-up plan;
- Side effects;
- Disease-free survival and overall survival (result of treatment);
- The date of death;

Additional or more detailed (health) data from the involved hospitals can be registered and processed for specific registration or research projects:

- For the Belgian Transplant Registry (BTR): the Belgian Cancer Registry registers and processes data from you if you, as a cancer patient, underwent a cell transplant (detailed information about your diagnosis, the type of transplantation, medication, outcome and complications, and follow-up) or if you have been a cell donor for a cancer patient (donor number, sex, date of birth, type of donated cell material, compatibility);
- For other registration and research project: for these specific projects you can request information about whether more specific data are processed, and if so, for which projects this is the case.

2.3 WHY DOES THE BELGIAN CANCER REGISTRY PROCESS HEALTH DATA?

The mission of the Belgian Cancer Registry is to collect and analyse cancer data and data collected for the purpose of the early detection of cancer in Belgium. Our activities can be divided into a number of categories. For example, we collect personal data in standard cancer registration and register data for the purpose of early detection of breast, cervical and colorectal cancer. Both activities are part of our statutory mission, in which personal and registration data are supplied by, for example, hospitals, health insurance funds and laboratories.

STANDARD REGISTRATION

The Belgian Cancer Registry strives for a complete and qualitative cancer registry. To achieve this, the direct submission of registration data from care programmes to the Cancer Registry is indispensable. Hospitals can submit clinical registration data directly to the Cancer Registry if they use their own application with secure file transfer via the Cancer Registry's website, or via the online WBCR application, which can be used by the hospitals as an application.

Hospitals with oncological care programmes and laboratories for pathological anatomy are legally obliged to cooperate with the Belgian Cancer Registry. The obligation to register these data is included in art. 11 Royal Decree of 21 March 2003 on care programs for basic oncological care and care programs for oncology.

In addition to standard cancer registration, the Belgian Cancer Registry also carries out a number of specific registration projects, beyond its legal obligations or on the basis of additional legal tasks. These projects are carried out in service of quality of care and for scientific research.

EARLY DETECTION OF CANCER

Since 2010, all anatomical pathology laboratories have been legally obliged to pass on all test results of breast, cervical and colorectal samples to the Belgian Cancer Registry. These cyto-histopathology registers are supplemented with the nomenclature data from the InterMutualistisch Agentschap (IMA)/L'Agence InterMutualiste (AIM). This reimbursement data concerns medical treatment relevant for the early detection of cancer, and the follow-up and treatment of (cancer)patients for which an early cancer detection test was done.

The Cancer Registry compiles among other documents exclusion lists in accordance with the law of 20 November 2017 regarding the protocol agreement between the Federal Government and the authorities as referred to in Articles 128, 130 and 135 of the Constitution, on the activities and funding of the Belgian Cancer Registry, Chapter 2, Article 4. These are lists of persons for whom screening is not (yet) necessary so that invitations can be sent out in a targeted manner, in cooperation with the treating physicians. The Belgian Cancer Registry compiles and passes the lists on to screening organisations, after authorisation by the Committee for Information Security:

- The Centre for Cancer Detection (CvKO) in Flanders;
- Le Centre Bruxellois de coordination pour le Dépistage et la Prévention des cancers (BRUPREV) in Brussels;
and
- Le Centre Communautaire de Référence (CCR) in Wallonia.

2.4 SECURITY

We recognise the importance and the need to process personal data securely. Absolute security does not exist, but the Belgian Cancer Registry strives for a high level of security. This means we take the necessary and appropriate measures to prevent unauthorised access, disclosure, alteration or the unauthorised destruction of data. Below is a non-exhaustive list of some examples:

- Annual information security training;
- Encryption of stored data;
- Password checks on applications that contain personal data via e-ID for e-health;
- Incident management;
- a strict internal separation between input (data collection) and output (data analysis);
- a User Access Management policy based on the need to know principle for all BCR staff that handle personal data.

2.5 STORAGE

The Belgian Cancer Registry takes appropriate measures so it does not store personal data any longer than necessary to achieve the purpose for which it was collected. In certain cases this period is determined by law. Once the retention period has expired, the personal data is deleted or made anonymous.

Legal retention periods are:

- Cancer registrations, up to 30 years after the death of the patient;
- Data sets for use in research, determined case by case in the deliberations of the Information Security Committee; and
- Data about tumour samples, which are stored in specific hospitals, up to 50 years after the sample was taken.

3. SHARING PERSONAL DATA

The Belgian Cancer Registry strives to, when possible, share its expertise by sharing anonymised data. It ensures that, when this data is shared, identification of the patient whose data is analysed, is impossible.

In addition, the Belgian Cancer Registry shares personal data in certain, well-defined cases: the Belgian Cancer Registry has the legal duty¹ to provide, at request of the data source, a completed and corrected copy of the data provided by the source. This exclusively concerns patient data supplied by the actual source. Personal data is also shared with researchers and research institutions, but this data is always encrypted.

It is also possible for personal data to be accessible to certain service providers that support the Belgian Cancer Registry in carrying out its activities, or where a service provider processes personal data on our behalf. In such cases we ensure that these parties handle personal data with the same level of care. To this end, we conclude the necessary contracts and make it compulsory for these parties to respect strict confidentiality.

The Belgian Cancer Registry does not share personal data with third parties for commercial purposes. In limited cases the Belgian Cancer Registry may provide certain personal data to government departments, for example, in the context of legal inquiries.

¹ Art. 138 §2, 7° of the Coordinated Law of 10 May 2015 regarding the performance of healthcare professions

4. YOUR RIGHTS

INDIVIDUAL RIGHTS

Every individual has the right to access his or her personal data. This includes the right to ask whether The Belgian Cancer Registry processes personal data about you, to obtain a copy of this personal data, and to obtain additional information, such as what personal data the Belgian Cancer Registry processes about you and for what purpose, with whom we share the personal data, how long we keep personal data, and where we collect the personal data. You may request an (electronic) copy of your personal data.

In addition, each individual whose personal data we process has the right to correct incomplete or erroneous information and to request that their personal data no longer be processed or be removed. In certain cases, the Belgian Cancer Registry may comply with requests for discontinuation/removal, for example when it is no longer necessary to store the personal data for the research project for which they were collected. We may not be able to comply with every removal request, for example, if we have a legal obligation to retain certain personal data or when we legally obtained the personal data for scientific research purposes and this research is still ongoing. If your request is not granted, we will always indicate the basis for which we may or must continue to process your personal data according to privacy legislation.

You can request that the processing of your personal data be put “on hold” for the period necessary to examine whether or not we are able to comply with your request for correction, discontinuation or removal. You can also request that we put the removal of your personal data “on hold” if you require these data in the context of a legal claim. In these instances, we will leave your data untouched unless we need your personal data for reasons of common interest, to protect other or for legal claims.

If you wish to exercise one of these rights, please contact us at the addresses listed below. You are required to enclose a proof of identity with any request (for example, a copy of the front of an identity card), so that we can be reasonably certain that we are communicating with the right person. In principle, the Belgian Cancer Registry has a month to respond to requests. This deadline begins from the moment we receive the request, and have sufficient information to handle it.

It should be noted that not all your data are registered with your name. More often, your data are processed via specific codes to ensure confidentiality. If we cannot identify you directly, we might have to request you to provide us with more information first, before we can give you more information about your personal data, and so we can exercise your aforementioned rights.

By e-mail: dpo@kankerregister.org

DATA PROTECTION AUTHORITY

Every individual has the right to lodge a complaint with the supervisory authority concerned. In Belgium, this is the Data Protection Authority. The Data Protection Authority can be contacted via:

Telephone: +32 (0)2 274 48 00

Fax: +32 (0)2 274 48 35

E-mail: contact@apd-gba.be

5. WEBSITE AND COOKIES

Our website collects certain personal data, such as your IP address, browser type, location data, etc. in logs. We use this information to further develop our website, and to be able to identify and solve, for example, server or connection problems.

Our website also uses Google Analytics to monitor traffic to and on the website. To do so it uses 'cookies', small text files that are saved on a computer and in which certain information is stored. Google uses these cookies to analyse traffic to our website and its use. Google transfers the information generated by the cookies to the United States. More information can be found via the following [link](#).

We would like to point out that cookies can be disabled or removed via the standard settings of your browser, often via 'internet options'

USE OF THE COLLECTED DATA

The user data is collected in order to enable the Belgian Cancer Registry to provide its services, as well as for Analytics.

DETAILED INFORMATION ABOUT THE PROCESSING OF PERSONAL DATA

Personal data is collected for the following purposes and by the following services.

The services in this section enable the Belgian Cancer Registry to monitor and analyse web traffic and can be used to track user behaviour.

Personal data collected by Google Analytics: Cookies and usage data.

Place of processing by Google Analytics: the United States

Google's Privacy Policy can be found via this link: [Privacy Policy](#)

Users of the Belgian Cancer Registry website can choose an opt-out with Google via this link: [Opt-out](#)

6. ABOUT THIS PRIVACY STATEMENT

The Belgian Cancer Registry may occasionally make changes to this Statement. We announce any changes via our website. We advise you to consult the latest version of this document: the date of the latest update is provided at the bottom.

7. UPDATES

This Statement is valid as of 25/05/2018 and was last updated on 14/04/2021.