

PRIVACY STATEMENT
BELGIAN CANCER REGISTRY

Belgian Cancer Registry



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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 and protect it. It is a legal requirement to register new cancer diagnoses with us, whether or not discussed at an MOC. 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 some cancers.

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 and can be reached at 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 Data Protection Officer.

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 examines, stores, and analyses information about cancer diagnoses, 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, as 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, in other cases the data is part of a registration, performed, for example, by a hospital.

The Belgian Cancer Registry collects the following data:

- Unique patient identifier, including demographic parameters (date of birth, sex, postal code) and unique identifier for care program and hospital;
- Diagnosis according to international classification, including incidence date;
- Tumour stage (cTNM);
- Conclusion of the pathological report (including pTNM);
- Treatment with reference to guidelines or justification of deviation;
- Follow-up plan;
- Side effects;
- Disease-free survival and overall survival (result of treatment);
- date of death;

The obligation to register these data is stated in art. 11 §1 of the Royal Decree containing determination of the norms the care program for oncological base care and the care program for oncology must meet in order to be certified of 21 March 2003.

2.3 WHY DOES THE BELGIAN CANCER REGISTRY PROCESS PERSONAL DATA?

The mission of the Belgian Cancer Registry is to collect and analyse cancer data in Belgium. Our activities can be divided into a number of categories. For example, we collect personal data in standard cancer registration and registration of screenings. 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. The Belgian Cancer Registry also carries out special registration projects, in addition to its statutory duties, as long as a patient grants permission for this.

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 services for anatomopathology are legally obliged to cooperate with the Cancer Registry.

In addition to standard cancer registration, the Belgian Cancer Registry also carries out a number of specific registration projects.

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 is reimbursement data concerning medical treatment relevant for the detection, follow-up and treatment of these cancers.

The Cancer Registry compiles 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 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. The Belgian Cancer Registry passes the lists on to screening organisations, after authorisation by the Committee for Information Security:

- For Flanders this is the Centre for Cancer Detection (CvKO);
- For Brussels is the Brussels Breast Cancer Screening Coordination Centre (Brumammo); and
- For Wallonia this is Le Centre Communautaire de Référence (CCR).

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 apply to:

- Cancer registrations, up to 30 years after the death of the patient;
- Incoming data sets, one week to a year after receipt;
- Data sets for use in research, determined case by case in the deliberations of the Information Security Committee; and
- Data about the physical storage of tumour samples, 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.

The Belgian Cancer Registry does share 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.

4. YOUR RIGHTS

INDIVIDUAL RIGHTS

Every individual has the right to access his or her personal data. This includes the right to ask whether 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.

¹ Art. 138 §2, 7° of the Coordinated Act on the exercise of health care professions of 10 May 2015

In addition, each individual whose personal data we process has the right to correct incomplete or erroneous information and to request the removal of his or her personal data. In certain cases, the Belgian Cancer Registry may comply with requests for deletion, for example if a patient withdraws his or her consent for registration. We may not be able to comply with every removal request, for example, if we have a legal obligation to retain certain personal data. Anyone that has granted his or her consent for a particular registration, has the right to withdraw that consent.

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.

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 may collect 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 diagnose, 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.

The personal data used for each purpose is described in the specific sections of this document.

DETAILED INFORMATION ABOUT THE PROCESSING OF PERSONAL DATA

Personal data is collected for the following purposes and uses the following services:

Google Analytics - 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 Brussels 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