



Belgian Cancer Registry

## BCR Code for data requests of for-profit organizations

v. 21/06/2024

### Preamble

The Belgian Cancer Registry (BCR) collects information about all new cancer diagnoses in Belgium. Based on this information it securely processes cancer data in the context of the nature and extent of cancer and cancer care. This includes the analysis of cancer data and the reporting on cancer, as well as the specific tasks mentioned in art. 138 Law of 10 May 2015 regarding the performance of healthcare professions.

Although BCR is financed through public means and therefore wishes to make cancer information available free of charge, it is nevertheless faced with an increasing number of external requests for data reports and statistics, mainly from for-profit companies. This leads to increased operating costs and also certain ethical concerns.

In line with the existing practices of other cancer registries across Europe, BCR has therefore decided to charge limited services fees for data requests of for-profit organizations under the terms and conditions of this *Code for data requests of for-profit organizations*.

### Requests for BCR data

Requests for data must be submitted and send to [info@kankerregister.org](mailto:info@kankerregister.org).

Requests shall be handled confidentially.

BCR fully reserves the right to decide in its sole discretion whether a request can be granted. In general, requests of for-profit organizations shall only be granted if:

- the requested data falls within BCR's **standard descriptive epidemiology** (i.e. classic cancer burden data, incl. cancer incidence, survival, prevalence and trends). Requests that require additional analyses and/or combining data from other databases shall not be granted under this Code.
- the request can be granted by providing **anonymized data**, meaning that the reports/statistics do not need to contain any personal data of patients (whether or non-pseudonymized) and no authorization of the Belgian Information Security Committee is required.

If the request can be granted, BCR staff shall make an estimate of the price setting (fees) for your request and communicate this fee estimate to you via the Data Request Form ("Data Request Form for for-Profit Organizations").

If you agree with the fee estimate, then you must complete the Data Request Form, sign it for approval and send the signed form back to: [info@kankerregister.org](mailto:info@kankerregister.org). **Submitting this form**

**means that you agree on behalf of your organization with the terms and conditions of this Code for data requests of for-profit organizations.**

Upon receipt of the signed form, the requested information shall be provided within approximately 14 days unless communicated otherwise. This delivery time is merely an indication.

## **Request Fees**

### ***Fee rates***

BCR request fees applicable as of *01 July 2024*

<b>Fixed fee per new request</b>	<b>€ 220, -</b>
<b>Fees for follow-up questions related to previous request</b>	<b>€ 110, - per hour started</b>

*Fees are exclusive 21% VAT*

BCR has the right to revise its fees from time to time, including a yearly indexation of the fees. The fees applicable at the time of submission of the data request shall apply.

### ***Payment terms***

Fees will be invoiced using the invoice data included in the relevant Data Request Form.

BCR will invoice at the end of each month in which the data request was granted.

Invoices must be paid within 30 calendar days from the invoice date using the account number and reference included in the invoice. In case of late payment, the Law of 2 August 2002 on combating late payment in trade transactions shall apply.

## **Ethical and legal conditions**

- 1. No selling of data.** BCR only charges fees for its services of providing anonymized data reports and statistics to for-profit companies. It does not charge any fees for patient data as such. Therefore, BCR will not charge fees (i) if the request relates to information already available on the BCR website (e.g., cancer fact sheets) or its other publications, in which BCR will refer the requestor to this information, or (ii) if the requestor withdraws its data request before BCR has started working on the request.
- 2. Data protection.** Within the scope of this Code, BCR shall never provide non-anonymized patient data to for-profit organizations. BCR shall only deliver fully anonymized statistics and/or reports in answer to the data request. The for-profit organizations shall at all times respect the sensitive nature of the source data and make no re-identification attempts whatsoever. They shall notify BCR immediately if -by accident- any non-anonymized patient data has been transferred and delete such data.
- 3. Data property.** BCR does not grant any intellectual property or other rights to its source data. BCR does not grant any intellectual property or other rights to the statistics/reports provided in answer to the data request either. BCR retains all intellectual property rights

to such statistics/reports, and only provides to requestor a non-exclusive, non-transferable, perpetual, worldwide, royalty-free license to use the statistics/reports.

4. **Research purpose.** The statistics/reports provide by BCR may only be used by the for-profit organization for the research purposes listed in the Data Request Form as approved by BCR. The research must in each case be relevant to combating cancer and must be in line with BCR's mission. The research must also be conducted by the for-profit organization in line with all ethical and legal research requirements and codes of conduct, and for-profit company shall take full responsibility for this. BCR makes all reasonable efforts as to the correctness and completeness of its sources data and the provided statistics/reports but does not provide any guarantee regarding satisfactory quality or fitness of the provided statistics/reports for the research purpose.
5. **Publications.** If the for-profit organization uses the statistics/reports provided by BCR to make publications, then it shall mention and acknowledge BCR in that publication as the source of those statistics/reports. The for-profit organization shall thereto use the following acknowledgment:

Belgian Cancer Registry, Brussels, YYYY
6. **Transparency.** The for-profit organization shall respect the Sunshine Act (if applicable, art. 41-48 Law of 18 December 2016 regarding various provisions on health) and/or similar applicable legislation, if any, and it shall thereto do the necessary reporting of the fees paid to BCR.
7. **Disputes.** If the for-profit organization does not comply with this *Code for data requests of for profit organizations*, then BCR has the right to refuse or cancel the data request, without prejudice to BCR's right to compensation of harm caused by the non-compliance. This *Code for data requests of for-profit organizations* is governed by Belgian law and any claims or disputes related to it shall fall under the exclusive jurisdiction of the competent courts of Brussels (Belgium) insofar these claims or disputes are not settled amicably.

