

Privacy Statement Netherlands Childhood Cancer Registry (NCCR)

Introduction

The Netherlands Childhood Cancer Registry (NCCR) collects medical data from children with cancer in the Netherlands. This helps us to make care better and better. The NCCR is housed at the Princess Máxima Center.

We handle information with care and always follow the rules of privacy legislation.

Who is responsible?

The NCCR Registration Holder manages the registration and is responsible for the security and content of the data.

The Princess Máxima Center is responsible for the processing of the medical data recorded there.

Why do we collect data?

We collect data to improve the care for children with cancer. We do this by:

- Learning what is going well and what could be improved.
- Helping patients, parents, and healthcare providers make choices about treatment and aftercare.
- Conducting scientific research (only with permission and approval by the scientific committee).
- Comparing with other countries to learn from each other.

No automated decision-making or profiling takes place based on your data.

What is the legal basis for data collection?

We process personal data on the basis of:

- Compliance with a legal obligation: To keep track of medical registrations.
- Compliance with a legal obligation: For quality improvement of care.
- Given consent: For the use of data for scientific research.

What data do we record?

The NCCR contains, among other things:

- Information about diagnosis, treatment and outcomes
- Data on long-term effects, such as heart damage or fertility

The data in the NCCR are pseudonymized. This means that identifying data such as name and address are not included. Only additional information (e.g. a unique code) can be used to create a connection, and this is done exclusively by authorized employees under strict security. In this way, we ensure that data cannot be traced directly to a person.

Who can view the data?

- Only employees with permission may view the data.
- Researchers may use data if patients and/or parents have given permission and if the science committee agrees.
- Data is never shared with others, unless legally required or if patients and/or parents give permission for this.

Which parties do we work with?

For the collection and processing of data, we work together with:

- Castor
- Netherlands Comprehensive Cancer Centre (IKNL)
- Performation

These organizations help us store and process data securely.

Who provides data?

The data is provided by healthcare providers who treat children with cancer or survivors. This data comes from the medical file. This is done without a name or address details.

Where is data processed?

The data is processed within the European Economic Area (EEA).

Sometimes data is used for scientific research. This is only possible if patients and/or parents have given permission. If data goes to a country outside the EEA, we provide additional protection according to the legal rules.

How do we protect data?

We take many measures to keep data safe. Security is regularly audited by external experts. The Internal Trusted Party oversees the security of the data.

What rights do you have?

You have the right to:

- Receive an explanation of what data is collected
- Access your data
- Have an error rectified
- Request that data be erased ('right to be forgotten')
- Request restriction of processing
- Transfer data to another party
- Object to the use of data

Because the data is not personalized, we cannot always meet every request. This is possible if you provide additional information so that we can find your details.

Opt-out policy

You have the right to object to the inclusion of your child's medical data in the Netherlands Children's Cancer Registry (NCCR). This is called an *opt-out*.

If you object, we will not include your/your child's data in the NCCR.

It is important that you are aware of this choice. Therefore, the Princess Máxima Center always informs you in advance. The opt-out policy gives you control over the use of medical data outside of treatment. This is in line with the rules of privacy legislation.

If you wish to exercise the opt-out option, you can send a request to the NCCR's data protection officer.

Cookies

We only use functional and analytical cookies on the website. You can read more about this on our [cookie page](#).

How long do we retain data?

We retain data for as long as necessary for the purpose of the registration and in accordance with legal requirements.

Supervision and independence

The Registration Holder works independently and without the influence from others. The Data Protection Officer (DPO) monitors our compliance with privacy regulations.

Contact

Do you have any questions about this privacy statement or about how we handle data? Please contact the data protection officer:

Registration Holder Netherlands Children's Cancer Registry (NCCR)

Attn: Data Protection Officer

P.O. Box 113

3720 AC Bilthoven

E: FG@prinsesmaximacentrum.nl

You can also file a complaint with the Dutch Data Protection.

Third-party websites

This privacy statement does not apply to websites to which we link. If you have any questions about those websites, please contact their administrators.

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