

PATIENT INFORMATION REGARDING NEFRODATA

Nefrodata

Nefrodata is the Dutch registry of kidney patients. Nefrodata is managed by the Nefrovisie Foundation in Utrecht (hereinafter: Nefrovisie). Nefrovisie is the national quality agency for kidney disease treatment.

Data are collected in Nefrodata about the treatment of all Dutch kidney patients who consented to this information gathering. This data can be used to determine whether the quality of care has improved or worsened. In this way it can also affect your treatment as a patient.

Nefrovisie acts as the controller with regard to data processing in Nefrodata in the sense of the General Data Protection Regulation (GDPR).

To get an accurate picture of the situation, Nefrovisie collects the following data:

- Personal information such as your name, date of birth, sex and postal code;
- Information about the cause of your disease;
- Information about the start of the treatment, the manner of dialysis, and any changes;
- Date of change of your healthcare institution/dialysis centre;
- In case of death: the date and cause of death;
- Clinical data such as laboratory results, medication information, possible other illnesses, hospital admissions, information about the shunt and infections.
- Results of the treatment that are important to you as a patient (PROMs).

Nefrovisie can use these data to:

- Give feedback to patients and healthcare institutions about the results of the treatment;
- Take stock of the number of (new) kidney patients in the Netherlands;
- Document the causes of kidney failure and death in the Netherlands;
- Find out more about the treatment patients choose (haemodialysis, peritoneal dialysis, at-home or nightly treatment, or refrain from these treatments);
- Determine the quality of the dialysis treatment per dialysis centre/healthcare institution;
- Determine and compare the quality of the dialysis centres/healthcare institutions in the Netherlands;
- Conduct scientific research with the aim to improve the quality of care for kidney patients.

Data exchange

To improve the data quality in Nefrodata, Nefrovisie exchanges information with the Dutch Transplant Foundation (Nederlandse Transplantatie Stichting, NTS), which is responsible for the registration of kidney transplants. In addition, Nefrovisie provides information to the European Renal Association (ERA) in order to enable a comparison among European countries.

For more information about Nefrodata and the national data, please go to www.nefrovisie.nl and www.nefrodata.nl

Nefrovisie

Your data in Nefrodata

Your data will only be provided to Nefrovisie if you give your permission for this to your healthcare institution. Nefrovisie also needs your consent to process these data in Nefrodata and to share them with the Dutch Transplant Foundation (NTS) and the European registry ERA.

It is up to you whether to consent or not. Participation is voluntary. If you do not give your consent, your health care institution will not send your data to Nefrodata. Nefrovisie will not be able to process your data in this case either.

You can give consent by completing the consent form, signing it and handing it in to your health care institution. Your healthcare institution will save the consent form in your medical file.

Want to revoke your consent?

You can revoke your consent at any time, without indicating your reason for doing so, if you no longer want your data to be processed in Nefrodata. The data that are collected and processed about you in Nefrodata will continue to be used until the moment that you revoke your consent. To revoke your consent, you can contact your healthcare institution. They will pass this on to us.

Retention period

We will save your (personal) data as long as Nefrodata exists.

Your rights

You have the right to view, correct and delete personal data about you. In some cases, you can also ask us to forward your personal data to another service provider.

If you wish to exercise the mentioned rights, you can send your request to your health care institution. You should clearly indicate which personal data these are. You cannot make this request directly to us, because we can't check your identity.

Nefrovisie

Want to know more ...?

... about your rights as a patient?

The Dutch Patient Federation (Patiëntenfederatie Nederland) protects all people who need health care. Contact the National Health Care Number at:

Tel: 0900 23 56 780 (20 cents per call)
Email: info@nationalezorgnummer.nl
Website: www.nationalezorgnummer.nl en www.npcf.nl

... about personal data protection

Our Data Protection Officer (DPO) monitors compliance of the applicable privacy laws and regulations. Our DPO can give you more information about the processing of your personal data, when you need additional information. You can contact our DPO at privacy@nefrovisie.nl.

More information about Nefrodata and privacy you can find at www.nefrovisie.nl/nefrodata-privacy. General information about personal data protection you can find at www.autoriteitpersoonsgegevens.nl

... about protection of medical data

The website www.rijksoverheid.nl has more information about the Dutch Medical Treatment Contracts Act (WGBO). Enter the search term 'patient rights'.

Complaints

If you have complaints about how we handle your personal data, you can contact us via the contact information as listed in this folder. We will be glad to help you find a solution. Should this be unsuccessful, you can always contact the Dutch Data Protection Authority. Go to www.autoriteitpersoonsgegevens.nl for more information about submitting a complaint.

Contact information of Nefrovisie:

Nefrovisie
PO Box 830
3500 AV Utrecht
088 770 55 00
registratie@nefrovisie.nl
www.nefrovisie.nl

Nefrovisie

CONSENT FORM

Processing of medical data by Nefrodata

YES

I consent to my health care institution providing my data to Nefrovisie.

I consent to Nefrovisie processing my data in Nefrodata and providing these data to the Dutch Transplant Foundation (Nederlandse Transplantatie Stichting) and the ERA.

INFORMATION OF THE HEALTH CARE INSTITUTION TO WHICH YOU ARE GIVING CONSENT

Name of health care institution:

Address of health care institution:

Postal code and city of health care institution:

NO

I do not consent to my health care institution and Nefrovisie forwarding my data and processing them in Nefrodata.

MY INFORMATION

Last name: M F

First initials:

Date of birth:

Date: Signature:

The above information is necessary for documenting your choice in your medical file at your health care institution.

In the event of (legal) representation, such as for a minor or a guardianship, please also include the name and signature of the representative.

Please return or send back the completed consent form to your health care institution, to be added to your file (please do not send to Nefrovisie).