

PATIENT INFORMATION REGARDING RENINE

Renine

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

Data are collected in Renine about the treatment of all Dutch dialysis 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 Renine 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 manner of dialysis, start of treatment and any changes;
- Date of change of your dialysis centre;
- In case of death: the date and cause of death;
- Clinical data such as laboratory results, information about the shunt and (vaccinations against) infections.
- Results of the treatment that are important to you as a patient (PROMs).

Nefrovisie can use these data to:

- Give feedback to patients about the results of the treatment;
- Take stock of the number of (new) dialysis patients in the Netherlands;
- Document the causes of kidney failure and death in the Netherlands;
- Find out more about the way patients are treated (haemodialysis, peritoneal dialysis, at-home or nightly treatment);
- Determine the quality of the dialysis treatment per dialysis centre;
- Compare the quality of the dialysis centres in the Netherlands;
- Obtain a national overview of the quality of treatments;
- Conduct scientific research.

Data exchange

To improve the data quality in Renine, Nefrovisie exchanges information with the Netherlands Transplantation Foundation (Nederlandse Transplantatie Stichting, NTS). In addition, Nefrovisie provides information to the European Renal Association - European Dialysis and Transplant Association (ERA-EDTA) in order to enable a comparison among European countries.

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

Your data in Renine

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

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 Renine. 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 the health care institution. Your health care 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 Renine. The data that are collected and processed about you in Renine will continue to be used until the moment that you revoke your consent. To revoke your consent, you can contact Nefrovisie using the contact information as listed in this folder.

Retention period

We will save your (personal) data as long as Renine 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 the contact information as mentioned in this folder. You should clearly indicate which personal data these are. We can ask you for additional information in order to check your identity.

Want to know more ...?

... about your rights as a patient?

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

Tel: 0900 235 67 80 (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. You can contact our DPO at privacy@nefrovisie.nl.

Go to www.autoriteitpersoonsgegevens.nl and www.rijksoverheid.nl/persoonsgegevens. For more information about the security measures taken by Nefrovisie, go to www.nefrovisie.nl/informatie-voor-de-patient.

... 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
info@nefrovisie.nl
www.nefrovisie.nl

CONSENT FORM

Processing of medical data by Renine

YES

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

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

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 Renine.

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).