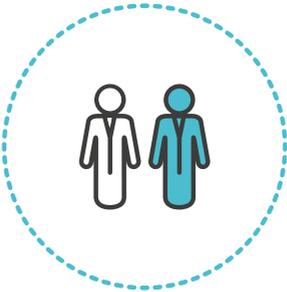


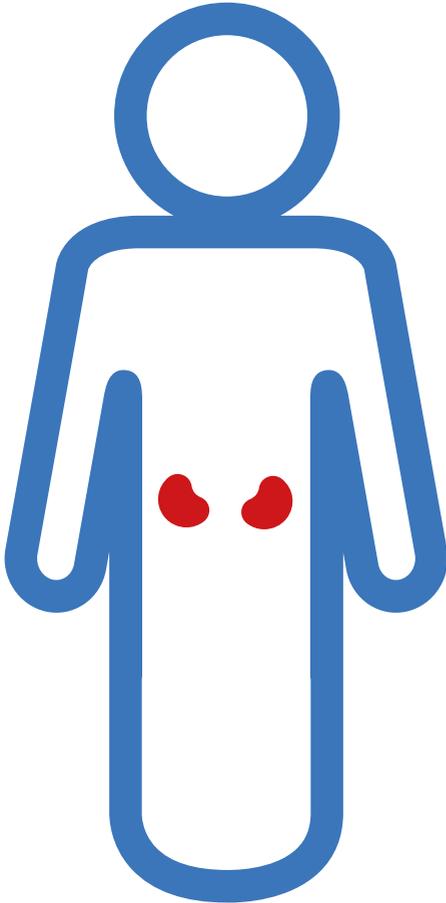


Will you help increase the value of research?

Information for kidney patients / donors



Will you contribute to research?



With high-quality scientific research, we can improve the quality of care and improve the lives of all kidney patients and donors. It ensures new insights for researchers into the causes of kidney failure. In this way, researchers get more insight into the causes of kidney failure. Furthermore, specialists can develop new treatment methods and caregivers can take the priorities of kidney patients into account.

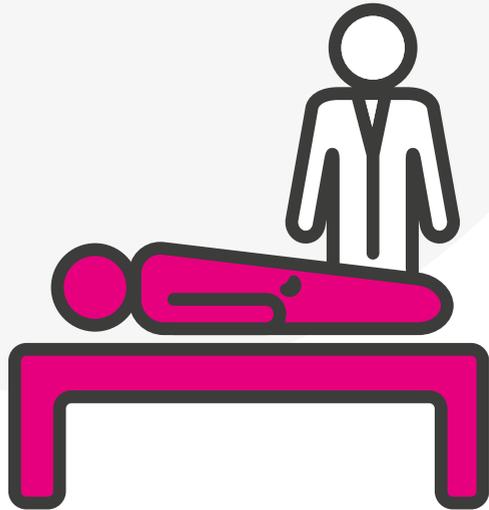
Good research is not possible without the contribution of kidney patients and therefore we urgently need your help. Your opinions, experience and knowledge can help researchers acquire a better picture and develop new insights.

Are you willing to cooperate on research? In this brochure you can read how you can make a valuable contribution.

The role of patients in research

This brochure is a shortened version of the policy document [De rol van patiënten in onderzoek](#) / [Patient Role in Research](#).

Research subject



As a research subject you participate in research or an experiment. For example, you might undergo a new treatment, test a new drug or allow blood tests to be performed. Participation is voluntary; so you always decide whether you wish to take part in a study.

Viola tested a drug to combat polycystic kidney disease

“In 2011, I visited a theme day of the Nierpatiënten Vereniging Nederland (NVN) / Dutch kidney patient association with my mother. In a presentation about the treatment of polycystic kidney disease, Doctor Gansevoort from Groningen talked about a drug that is used to inhibit the growth of intestinal cancer tumours. This drug, named Lanreotide, might also have an inhibiting effect on the growth of certain cysts.”

“Lanreotide had already been tested in a small-scale study. The results were so promising that more extensive study into the effect on polycystic kidney disease was needed. To this end, they were looking for 300 people, aged between 18 and 60, with renal function between 30 and 60%.”



“I met the requirements and applied, via my nephrologist, as a guinea pig. I sincerely hope that Lanreotide can inhibit or halt the growth of cysts in kidneys or even reduce existing cysts. I’m convinced that the research is a major step in controlling polycystic kidney disease. And I’m lucky that I have been able to contribute and may even get ‘better’ from it.”



This is how you can take part

Sometimes researchers are looking for people who are willing to take part as research subjects. If the NVN is well-informed about the research and also supports the idea, then we publicise it, for instance in our magazine *Wisselwerking* or during theme days. However, registration is always handled directly via the researcher or specialist. The NVN does not have any role in mediation.

Information provider



As an information provider, you answer questions from researchers. There are different ways to do this. For instance by filling in a questionnaire, participating in a personal interview or in a (focus) group debate.

Anneke is an active member of NP online

Opinions and experiences of kidney patients, their family and friends and donors are important in order to improve the quality-of-life and care. Anneke van der Stouwe joined up right at the start of the patients' survey panel NP online. She regularly completes questionnaires and takes part in debates.



Anneke: "It's not much effort. If I get a request, I can decide when I want to fill in the questionnaire. And I can pause while filling in a longer questionnaire to do something else. I can always finish it at a later moment. When it's not convenient, I can always skip a round. But I can't remember that ever happening.

"I think the group debates are useful but also fascinating. Not only for the researcher and the NVN, but also for me. I hear the stories of other experiential experts and I'm sometimes surprised by other opportunities or new developments. It's also very enjoyable! I can recommend it to everyone."



This is how you can take part

Do you want to take part in research as a provider of information? The NVN has set up NP Online. If you register, you will receive questionnaires several times a year about scientific research and current issues. You don't need to be a member of the NVN to take part in NP online. It is easy to register via www.nponline.nl.

Questionnaire evaluator



Questionnaire evaluators critically assess a draft questionnaire before it is sent to a large group of patients and/or their families. As evaluator, you indicate what is unclear or difficult in the draft. Your feedback helps to develop a good and apt questionnaire that is attractive for patients to complete. As a questionnaire evaluator you work individually; you can do this work at home on your computer.

Lammert helped improve shunt care

Lammert Kooi is on haemodialysis and works as questionnaire evaluator on an investigation of clinical guidelines for vascular access care for haemodialysis patients. The aim of the investigation is to improve shunt care in the long run. Together with other kidney patients, Lammert has examined the questions and provided feedback.



“If you want reliable answers to questionnaires, you have to pose the right questions. A description such as ‘failed puncture’ can have different meanings for patients. For one it’s a real failure, when you don’t manage to penetrate the blood vessel. For another it only means you try again. I enjoy helping in

this way and it’s very motivating to see the results afterwards. What I also like is that it gives you an opportunity to look at your sickness from a different angle. More reflective and from a distance. I find it satisfying that I’m not the only one to benefit from improvements, but other patients do too.”



This is how you can take part

Are you a member of the NVN and interested in this function? Then please contact secretariaat@nun.nl as a volunteer.

Adviser



As an adviser, you are part of a feedback or advisory group that comes together at important moments during the study. This is usually between three and six times a year. You cooperate actively in the organisation or execution of a study. For instance, you check if research subjects are not burdened too heavily, the patient information is clear and that participants have a way to pose their questions. You discuss the results and help think about the next phase of the study.

Caroline takes part in research as an adviser



Caroline spent more than a year in a feedback group to study the needs of kidney patients with moderately to severely reduced kidney function.

“As an adviser, I get appreciation and an opportunity to have a say. I notice that my opinion counts. I hear the stories from other patients and recognise a lot. I really enjoy taking part in research.

“I expect that the research I am working on will result in more attention for people with moderate to severe reduced kidney function and I hope that the research results lead to improved care. For instance through recognition by doctors in a way that goes beyond only medical care.”



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Reviewer / commentator



A reviewer critically reviews a research proposal from the patients' perspective. You focus on issues such as the level of burden placed on research participants, communication with research participants and the way in which experiential experts are involved in the organisation or execution of a study.

The NVN has a fixed group of patient evaluators who participated in a training for this function. They meet two to three times a year to evaluate research proposals from the patients' perspective. In between, they evaluate proposals by e-mail.

Gert evaluates grant applications for scientific research

Gert van Pelt has about 40% renal function. In cooperation with doctors and chemists, he evaluated grant applications for scientific research on the viability, usefulness for kidney patients and other criteria.



“We have evaluated about 35 applications, of which about 20 were accepted. Fortunately there was mutual agreement on which projects were important for kidney patients. It struck me that people listened attentively to my contribution; I hadn't expected that. That was not only pleasant to notice, it also meant that my experiences as a kidney patient were considered in the discussion.

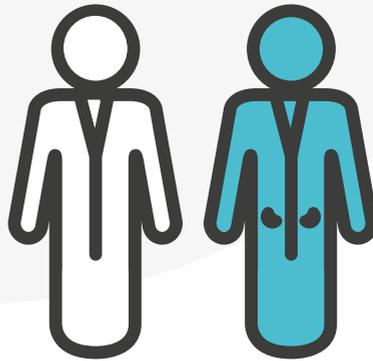
“My participation in the advisory commission was a wonderful opportunity to apply my experience and knowledge directly for kidney patients. It is really a pity that I can't do voluntary work like this every day!”



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Co-researcher



As co-researcher, you are part of the research team and carry out part of the research. You are involved in determining the themes that will be investigated, conduct interviews or facilitate a (focus) group discussion. In addition, as a research partner you examine the research results critically.

The function of research partner is an intensive voluntary position, compensated by a volunteer's fee. The exact details will be discussed with you in close consultation and, of course, depend on the level of burden you can take.

Leon is part of the research team “More independent and less tired”

“My daughter Jette has a transplanted kidney and yet she is still often tired. That is of course difficult for her, but it also makes me wonder: why is she tired? Surely that isn't necessary? These questions led me to take part in the research project ‘More independent and less tired’.

“At first I was involved in developing a protocol for a psychosocial treatment for dialysis patients. Now I am conducting interviews with medical social workers and patients in the cooperating hospitals and dialysis centres. I also maintain contact with a feedback group of experiential experts; They give us feedback and



ensure that we continue on the correct course. Making a newsletter is also part of this task.

“I have a serious position in the research team, where my contribution is highly valued. There is also plenty of room for own initiative. It regularly demands a considerable effort, but I don't mind that at all: my contribution is for a good cause!”



This is how you can take part

Are you a member of the NVN and interested in this function? Then contact secretariaat@nun.nl as volunteer.

You want to know more?

If you want to know more about how you can contribute to research or have questions as a result of this brochure, then please contact the NVN: secretariaat@nvn.nl or +31(0)35 - 691 21 28..

About the Nierpatiënten Vereniging Nederland (Dutch Kidney Patients' Association)

The NVN helps kidney patients maintaining and/or improving their quality of life and care. We are an active association of and for people with chronic kidney failure, their relatives and kidney donors. With about 8000 members, the NVN is a powerful representative of the interests of people with chronic kidney disease.

Contact

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Nierpatiënten Vereniging Nederland