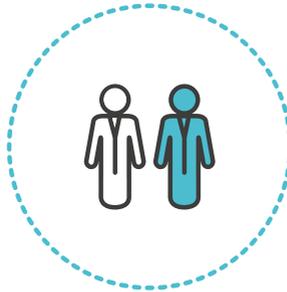
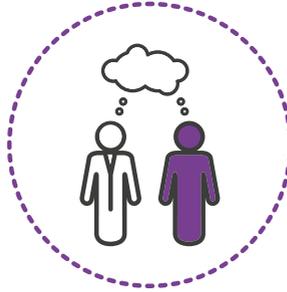
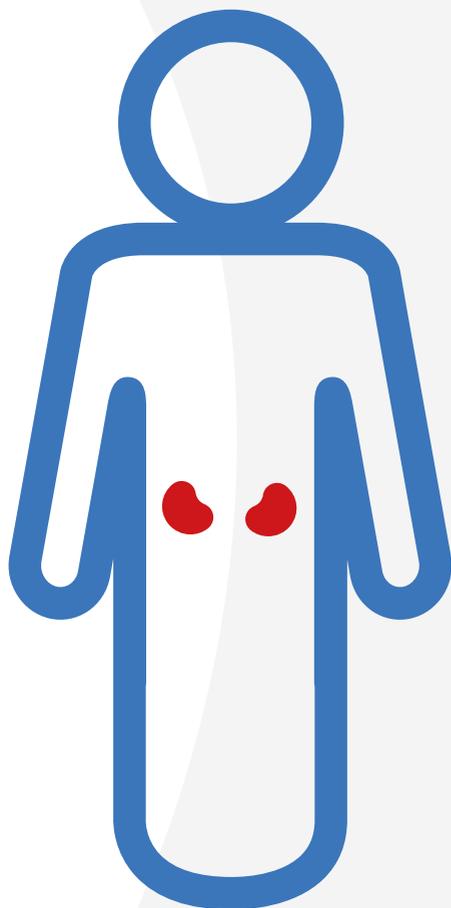




The added value of patients in research

Information for researchers





The added value of patients in research

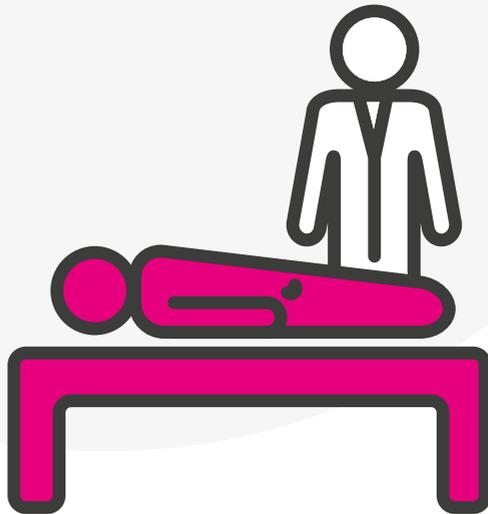
With high-quality research, we can improve the quality of care and life for all kidney patients and donors. It ensures new insights for you, as researcher, into the causes of kidney failure. Furthermore, specialists can develop new treatment methods and caregivers can take the priorities of kidney patients into account.

Good research is not possible without the contribution of kidney patients. Their opinions, practical experience and knowledge helps you to get a better picture and acquire new insights. This brochure explains the ways in which patients can make a valuable contribution to your research.

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 subjects



Research subjects are essential in research, for instance into new treatments. Usually, researchers themselves approach participants for their studies. However, the NVN can play a role by focussing extra attention on the research through their own media: under the condition that the NVN is involved in the research process. Researchers can also place a request for research subjects on our forum or in our Facebook group.

Sympathy, a new treatment for high blood pressure

Led by the UMC Utrecht, scientists are further investigating a new treatment (renal denervation) in which the functioning of renal nerves is blocked. These nerves are located around the arteries and largely regulate blood pressure. This might be a solution for people with high blood pressure, especially for those who experience many side effects from their medicines or for whom medicines don't work.

With the Sympathy study, the investigators are trying to discover the precise functioning and effectiveness of the treatment. Moreover, the long-term effects of the treatment and whether the treatment is effective for patients with a reduced kidney function are studied.



UMC Utrecht

Client:

UMC Utrecht Research Institute

Applicant: Dr. P. J. Blankestijn

Grant provider

ZonMw, Nierstichting

About 15 Dutch hospitals cooperate in the Sympathy study. The NVN is taking part in the feedback group. For instance, the NVN judges the burden for participating patients and whether patients are involved in a satisfying way. Knowing that the research was well organised, the NVN informed kidney patients about the Sympathy study.



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This is how it works

The NVN can publicise your research in its members' magazine *Wisselwerking* or during theme days. We are willing to do this if we are involved in the research, for instance if experiential experts from the NVN are in the advisory or feedback group. If you're interested, please contact us before the start of your research. In addition, you can place a request for research subjects on our forum or in our Facebook group. The mediation between research subjects and researchers is the responsibility of the researcher or specialist.

Information providers



Researchers can distribute a questionnaire via NP online: the online panel of the NVN. They can either develop the questionnaire themselves or in cooperation with us. NP online also offers an opportunity to invite panel members for an interview or group discussion. Currently, more than 500 people are registered with NP online and that number is still growing. Because the respondents consciously chose to participate with NPonline, we usually see high response rates.

Experiences with Dialysis

The health science Department of the Universitair Medisch Centrum Groningen (UMCG) is developing a psychosocial treatment for people on dialysis. With this treatment, the UMCG wants to improve self-management for dialysis patients. Experiencing control over one's own life is important for the quality of life of people.

To align the treatment as closely as possible to the desires and needs of people on dialysis, the UMCG has recruited respondents via NP online. Eighteen people responded to the request.



Researcher Alicia de Vries: "It was very interesting and useful to talk to people about their experiences with dialysis and the impact on their everyday lives. We spoke to all 18 people who responded, two of them by telephone because they lived far away. All others were interviewed personally."



This is how it works

Do you want to distribute a questionnaire or invite panel members for a (focus group) interview? Please send an email to nponline@umcn.nl or call 31(0)35 691 21 28

Questionnaire evaluators



The NVN has a group of questionnaire evaluators who critically assess a draft questionnaire before it is sent to a large group of experiential experts. The language used by a researcher is not always easy for a patient to understand. Certain sentences might for example cause irritation, leading to a low response rate. Part of this miscommunication can be prevented by having patients assessing this questionnaire first.

SHaRE - kidney disease project

As a result of their illness, kidney patients might experience sexual problems and reduced fertility. These changes can influence their relationships and quality-of-life. The medical team as well as the patient and partner often find it difficult to talk about these topics.

In order to improve care for kidney patients, the Sexual Health and Relationship Enhancement (SHaRE) kidney-disease project has been set up. In the project, care in the field of sexuality, fertility and relationship quality is evaluated using questionnaires. Before such a questionnaire is sent to kidney patients and their partners, experiential experts first take a critical look at it. Is



the questionnaire understandable? Are any important questions missing? Is the questionnaire pleasant to complete?

With information acquired from completed questionnaires, the SHaRE research team acquires insights into the way in which today's care approaches sexuality, fertility and relationship quality. Consequently, care can be improved when necessary.



This is how it works

Do you want to submit your questionnaire to our questionnaire evaluators? Please contact the NVN: secretariat@nvn.nl or +31(0)35 - 691 21 28.

Advisers



As researcher, you can complement your feedback or working group with experiential expert advisers. They provide advice about executing research from the patient's perspective. Think, for instance, of the burden on and communication with patients or developing patient information.

Development of a portable artificial kidney

The Nierstichting is developing a portable artificial kidney: a manageable haemodialysis machine that has advantages compared to current dialysis machines. It is easy to transport, so patients can dialyse more often and for longer periods. This will help them feel more energetic and they will need less medicines and a less strict diet.

A group of advisers, made up of thirteen kidney patients, their partners and care professionals, cooperates on developing the portable artificial kidney. Commissioned by the Nierstichting, Design Innovation Group has performed a user study. All the advisers were interviewed, subsequently various scenarios were discussed in a focus group: what are the requirements for home dialysis? And dialysis at work

or on holiday? Advisers also have raised new wishes: for instance, can the machine be taken on board an aircraft in a wheeled suitcase?

Researcher Nathalie Waser: "In order to develop a machine that patients are eager to use, it's very important to get to know them. The interviews provided useful insights into their needs, limitations and desires."

With the results, the developers are continuing to work on the portable artificial kidney that shall be available for tests from 2017.



This is how it works

Do you wish to cooperate with our advisers?
Please contact the NVN: secretariaat@nvn.nl
or +31(0)35 - 691 21 28.

Reviewers / commentators



Do you have a research idea or proposal? You can consult the reviewers of the NVN. They assess the idea or proposal using several criteria, such as the burden on and communication with research participants and the way in which experiential experts are involved in the research.

The reviewers have been trained specifically for this purpose. To protect your idea or plans, they have also signed a confidentiality declaration.

Don't start dialysis in the last stages of renal failure

For internal financing by the St. Antonius Research Fund, the NVN reviewed a research proposal about “prognosis and decision-making surrounding not starting dialysis in the last stages of renal failure”, commissioned by the St. Antonius Hospital. Two experiential experts reviewed the proposal from the perspective of patients and focused on issues such as relevance, the burden on the patient and communication with the patients. A NVN staff member provided advice on possible links with other national developments with which the NVN is involved. The NVN also provided feedback on a concept questionnaire that was developed by the researchers.



Client: Sint Antonius Hospital
Applicant: Dr. Willem Jan Bos
Grant provider:
Sint Antonius Research Fund

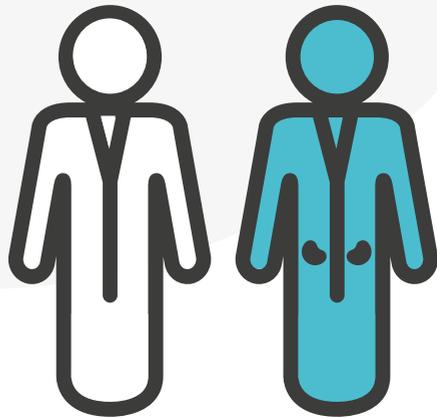
Internist-nephrologist Willem Jan Bos: “The contributions from the NVN provided significant added value for our research. It resulted in an improved understanding of how a study or questionnaire is experienced by the patients and we were able to make timely changes.”



This is how it works

Do you want to present your research idea or proposal to our patient evaluators? Please contact the NVN: secretariaat@nvn.nl or +31(0)35 - 691 21 28

Co-researcher



Patients can also be part of your research team and perform certain tasks together with you. They can, for example, help to formulate research themes or conduct interviews. They are able to give depth to the contact with those interviewed and as a result they bring valuable information to the surface.

More independent and less tired

The project “more independent and less tired” by the VUmc in Amsterdam focuses on developing a short-term psychosocial treatment for dialysis patients with fatigue in order to reduce fatigue and improve the quality of life. The fatigue is often correlated with stress, a lack of social contacts, fear and sadness.

Two co-researchers from the NVN are part of the research team. They are involved in all aspects of the study: from formulating information letters, questionnaires and protocols, conducting interviews, providing information in hospitals and dialysis centres to analysing data and writing reports. They also check whether the homework and questionnaires for the patients are not too burdensome.

The VUmc logo, consisting of the letters 'VUmc' in a blue sans-serif font followed by a stylized blue graphic of three curved lines representing a hand or a signal.

Client: VUmc

Applicant: Dr. Karen Schipper

Grant provider:
Nierstichting

Researcher Karen Schipper: “As researcher you cannot put yourself in the position of the patient. It’s invaluable to consider the perspective of the patients constantly; it really improves research. For instance, METC indicated they had never seen such a clear information letter for patients!”

A white lowercase letter 'i' inside a blue speech bubble shape, which is part of a larger dashed white line graphic that curves across the bottom of the page.

This is how it works

Do you want to set up and complete your study with one of our co-researchers? Please contact the NVN: secretariaat@nun.nl or +31(0)35 - 691 21 28.

You want to know more?

In this brochure, you have been able to read about the added value that patients might have in your study. The NVN is a professional patients' association with paid staff, but also always uses voluntary, trained experiential experts. There is a charge for our efforts; costs include working hours of staff members, travel expenses of volunteers etc.

If you want to know more about the possibilities of involving patients in your research, the costs involved or if you have any questions regarding this brochure, 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