



# Patient Role in Research

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# Foreword

**Since long the Nierpatiënten Vereniging Nederland (NVN: Dutch Kidney Patients Association) has been involved in research in various ways, but our role and position were not always clear. With this document we would like to change this.**

This document is based on the (draft) paper ‘De rol van patiënten in onderzoek’ (Patient role in research). This paper was discussed among a few members of our association and with the Nierstichting (Dutch Kidney Foundation) we now make it public to clarify our position in the research area and to strengthen the role of patient participation in research. The discussion can be put into a larger perspective. Redefinition of our volunteer policy has resulted among others in the formation of knowledge groups on specific themes. In these knowledge groups people not only share their experience, but also actively search for new developments and insights and formulate questions about necessary research and missing knowledge. It deals with the role a professional patient organization can play in research, considering her extensive experiential knowledge.

## **Acknowledgements**

This paper was realized thanks to the input of many people. Hans Bart, Karen Prantl and Marjolein Storm of the association’s national bureau shared their knowledge. We are also very grateful for the input by Meralda Slager, former secretary of the programme ‘Patient participation in research, quality and policy’ from ZonMw (The Netherlands Organisation for Health, Research and Development). We would also like to thank Karen Schipper of the Metamedics Faculty of VUmc (Free University medical centre). Last but not least we appreciate the important contribution by Cees Smit. Cees is an experienced patient expert, who has been active in many patient movements in the Netherlands and Europa, as well as within ZonMw. The NVN invites everyone, inside the association or beyond, who wants to contribute to take this issue any further, to join in the discussion or give feedback. We can all learn from it.

*The Board of the Nierpatiënten Vereniging Nederland*

# 1

## Introduction

**In 2012 the NVN was actively involved in several research projects. In one or two cases the research question came directly from our members. It concerned an inventory of the situation of people suffering from mild to moderate chronic kidney damage. In other cases the research proposal was written together with the Nierstichting. For example a research into the bottlenecks concerning the choice of dialysis treatment. In both cases the NVN was the contractor for the research project and the VUmc executed it. Several times we were requested to recruit research subjects, i.e. for promotion research at the Erasmus University Medical Centre.**

Regularly the NVN is approached by research institutes to support in various ways or commit herself to grant requests addressed to the Nierstichting, ZonMw or the European Union. We might assist in the research design, recruit research subjects, co-read and comment on research reports and participate in the implementation of research results.

Finally the NVN also initiates research, financed with third party funds. Like in 2012, to carry out a labour market survey (Maastricht University) and a research into chronic disease and reintegration (Groningen University).

### **Appeal on those we represent**

These forms of cooperation have one thing in common: patient perspective is always the angle from which a research question or design is approached, the research is carried out or the outcomes are implemented. We appeal directly to the experience expertise of our members, by involving a representative group of people with chronic kidney damage in the whole process. Or indirectly through member consultation. The national bureau collects this knowledge and shares it with the researchers. Since November 2013 we use the online tool NP online (Kidney patient Perspective online) for member consultations. This platform allows us to question kidney patients, both members and non-members, on various subjects.

### **Reading directions**

To stress the importance of NVN involvement in research, we first describe which role patient organizations can play in research<sup>1</sup>. Next we elaborate on the bottlenecks this involvement may cause. Finally we propose preconditions for maximum involvement of patient organizations and pragmatic solutions to these bottlenecks.

### **Ongoing process**

In this document we do not give a conclusive description of research participation. On the contrary, we want to start a discussion in a certain direction. Where this will end, the future will tell. We consider this an ongoing process and use this paper also to place some critical notes to our position and our focus.

In August 2013 we discussed the paper ‘De rol van patiënten in onderzoek’ with the Nierstichting, an important financier of nephrology research projects. Since then, we try to test these roles whenever we cooperate. For instance in a social science research call from patient perspective, the NVN denoted their attention points for incoming fund requests. A NVN representative also participated in the discussion that took place within the scientific council of the Nierstichting. The NVN considers this a favourable development.

But this document stretches further than research projects that are financed by the Nierstichting. It also includes promotion research, research financed by ZonMW and research in European perspective. We want to sketch the widest possible framework.

<sup>1</sup> *Patient participation does not only concern research, but also the definition of guidelines, care standards and (government) policies. In this article we concentrate on research.*

# 2

## Some literature on patient participation

**In 2007<sup>2</sup> Abma and Broerse published ‘Zeggen-schap in wetenschap’ (A shared say in Science). In their book they conclude that patient participation in research is still in an elementary stage in the Netherlands.**

**The object-subject dualism is the dominant scientific paradigm at that moment. Meaning an objective researcher studies the subject, taking certain distance. Repetition, representativeness and generalizability are the main criteria.**

### **What’s the truth?**

Abma and Broerse draw attention to another paradigm: the constructive scientific paradigm. This implies the scientist cannot define or know the truth in the world around him, since the human perception, thus that of the researcher, is prejudiced by his background, experience and interests.

Therefore it is important that the various stakeholders make their perceptions explicit in order to reach a common view on the complex reality. ‘True’ is what they agree on to be true (intersubjectivity). It concerns a reality in which both medical and psychological, cultural, social, political, organizational and financial aspects play a role. Dialogue is the central theme.

According to Abma and Broerse the researcher is not only observer and analyst; he is also facilitator to other research participants. Implying that people with a chronic affliction who participate in the research

process, should be trained in their role and in how they communicate with other stakeholders in their role as contributors to the dialogue. This training should not influence the uniqueness of their experiential knowledge.

Important criteria are:

- inclusiveness (i.e. specific groups of a certain ethnic/cultural background, specific age groups),
- credibility (check if participants recognize themselves in the interpretations, whether or not based on a combination of methods)
- fairness (protect the input of all stakeholders, both during the process and in the results)
- authenticity (see also the remark on training)

### **Patient participation during the entire process**

Patient participation in research is inspired by substantive arguments (better and more applicable knowledge), by values and political arguments (*empowerment*, the right to be involved in research) and to improve the cooperation among researchers. Abma and Broerse state that all stakeholders should be involved in the entire research process: defining the research agenda and design, collecting and analyzing the data, writing conclusions and recommendations and distributing and implementing the outcomes.

<sup>2</sup> Of course there are publications and projects on patient participation in research and policy making previous to 2007 among others by ZonMw. Abma's e.a. conclusion was a starting point for further exploration.

### Shared research agenda

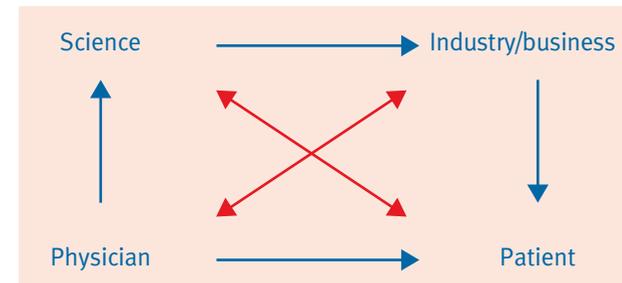
More publications were issued. In 2007 Abma et al. published the research report 'Leren over lijf en leven' (Learning about body and life)<sup>3</sup>, followed by a popular issue in 2011. In this report she identifies seventeen critical moments in the disease history of kidney patients, eleven critical moments in the daily life of adult kidney patients and several moments that are specific for various groups. This can be used to define a shared research agenda, at least for the social science research field.

### Multidisciplinarity leads to new insights

In January 2012 Karen Schipper, a kidney patient herself, obtained her doctorate with the research 'Patient participation & knowledge'<sup>4</sup>. This study shows that concepts like independence, participation, patient perspective, (experiential, practical en expert) knowledge, the role of patients as research partners and the importance of multidisciplinarity in the process of mutual learning and empowerment are meaningful for the entire research team. Moreover it leads to new and sometimes better insights.

### From Linear to interactive

Another book saw the light in 2012: 'Een nieuwe horizon' (A new horizon) by Cees Smit<sup>5</sup>. This book deals with more than just social science research. Smit elaborates on the role of patient (organizations) in both fundamental and drug research. On the latter Smit argues that instead of a linear model (science → industry/business → physician → patient) an interactive model is more the case:



Patient organizations have become part of the research network and are influential in that area. This brings along a new responsibility for both the spending of the (limited) financial means and the protection of (the privacy of) their members. Especially in the case of rare afflictions like hereditary kidney diseases it calls for an international scope.

As it turns out fundamental research shows more examples of good ways of cooperation between researchers and patient organizations. One worth mentioning is the study into the portable artificial kidney by the Nierstichting. The input by NVN member patients has led to substantial new and additional insights.

<sup>3</sup> T. Abma, C. Nierse, J. van de Griendt, K. Schipper, E. van Zadelhoff, 'Leren over lijf en leven. Een agenda voor sociaal-wetenschappelijk onderzoek door Nierpatiënten', Universiteit Maastricht, January 2007

<sup>4</sup> K. Schipper, 'Patient participation & knowledge', VU University press, Amsterdam, 2011

<sup>5</sup> C. Smit, 'Een nieuwe horizon. De toekomst van de patiëntenbeweging in Nederland', Kirjaboek, Hoogwoud, 2012

Smit argues that besides the traditional roles of a patient organization (giving information, organizing mutual contact and advocacy in the broadest sense of the meaning) an additional fourth role has arisen: active participation in medical scientific research and policy making, with fundraising consequently following that role, of which there are examples at hand.

### Horizontal Participation ladder (scale)

In various publications on the role of patient organizations in research the participation ladder is introduced. Smit substitutes the vertical Participation ladder<sup>6</sup> by a horizontal one<sup>7</sup>: based on PatientPartner workshops:

Obviously the most left position represents the traditional role of patient participation. Further to the right more recent roles are introduced, that until now, have

taken place less often. A horizontal view is preferable to a vertical one, since all roles exist simultaneously and are equally important. The research subject will always play a role of major importance.

Placed in the traditional vertical position Arnstein's (its creator) Participation ladder suggests a hierarchy. Participation in the form of research subject is at the lowest position, assuming it to be less important than the initiator or driving force. In a patient consultation during the PatientPartner project organized by the Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP - the Association of Cooperating Parent and Patient organizations), the patients objected to this. In their opinion input at all levels is important. The ladder is therefore placed in a vertical position. The equivalence of roles appeals to many people.



<sup>6</sup> Among others in Abma, e.a., 'Zeggenschap in wetenschap', Lemma, Den Haag, 2007, from page 127

<sup>7</sup> See Smit, 'Een nieuwe horizon', Kirjaboek, Hoogwoud, 2012, from page 132

# 3

## Interlude

**Literature shows a lot of development and progress in patient participation. Patient organizations are a source of knowledge that can lead to new and different insights. This is the case in fundamental, as well as drug or social science research. Participation is possible and important in all aspects.**

However, a few side remarks can be made to this positive conclusion. Placed in a broader European context, Keizer<sup>8</sup> concludes in 2012:

*“More in general, many respondents had the feeling that the whole issue of patients’ participation is still not taken seriously by all stakeholders. This could partly be blamed to doubts about the effects of participation. Some policy makers even suggest that participation only leads to generating more costs. One of the explanations for this could be that there is a knowledge gap between policy makers and the patients’ organizations, and that too little information about good practices, positive results, etc. is conveyed to these and other stakeholders.*

*This might also be the explanation for the observation that most governments adhere today to the principles of involvement of consumers/ patients, but this is very seldom translated into a coherent and comprehensive governments policy, aiming at stimulating this involvement.”*

In the Netherlands as well, it is not always clear which structures or principles of organization can best be chosen to get maximum outcomes. There is a distinction between the role of patient organizations and health funds<sup>9</sup>, private initiative that has its own logic (for example different actions from particular initiatives to raise money for the same disease), the role of ZonMw and the Netherlands Organization for Scientific Research (NWO), of the pharmaceutical industry, of European and national governments and the importance of research institutes.

In 2007 the Raad voor Gezondheidsonderzoek<sup>10</sup> (Health Research Council) stated that various activities in the area of patient participation should take place in a more systematic way. They also stress the importance of systematic support of patient organizations in research participation. This resulted in the joint ZonMw/ VSB Program: ‘Patient participation in research; quality and policy’, of which the outcomes are due by the end of 2013.

<sup>8</sup> B. Keizer, ‘Exchanging knowledge on participation of health consumers and patients in research, quality and policy’, ZonMw, Den Haag, 2012

<sup>9</sup> In the Netherlands we have the Dutch Kidney Foundation and the Kidney patient Association. Other countries don’t have such a distinction.

<sup>10</sup> Raad voor Gezondheidsonderzoek, ‘Patiëntenparticipatie in gezondheidsonderzoek’, Den Haag, 2007, issue 56

# 4

## Our role in research and how best to fulfil it

**As the participation ladder shows, patient organizations can play six (different) roles in research, namely that of:**

1. Research subject
2. Informant
3. Advisor
4. Reviewer/commentator
5. Co-researcher
6. Initiator / Commissioner

Just like many other patient organizations, the NVN has gained experience in all of these roles during the past years. We discovered that every role has its challenges and bottlenecks. For instance, how does one deal with the research agenda, when on the one hand one wants to have a say about what is placed on the agenda and be able to judge the research proposals, and on the other hand one wants to be in a position to send in research proposals? This chapter deals with this and other dilemmas.

To be able to play these six roles in the future, the related bottlenecks should be resolved. Our ideas on how to resolve these bottlenecks we would like to present to the reader.

### **4.1 Patient association as a source of research subjects**

When patient associations are requested to recruit subjects for research, they have to take a couple of things into account:

#### **Members' privacy is no. 1 priority**

According to the Privacy Act, the NVN is not allowed to pass on data about its members without their permission. And of course the NVN will never do this. When the NVN is convinced of the importance of the research, we will actively approach our members to ask if they are willing to participate in the research. If they are, the NVN will bring them into contact with the researchers.

Another possibility to recruit research subjects is to place an announcement on our website, Facebook or in our magazine *Wisselwerking* (Interaction). Members who sign in as research subjects, explicitly give permission for their personal data to be used. It is possible to encrypt the data to guarantee the member's anonymity. The NVN makes sure everything necessary is done to protect the personal lives of its members.

### **Up-to-date member administration costs time and money**

To be able to select the research subjects that are vital to the research, the NVN should have its member administration in order and up to date. Only then target groups can be accurately specified and (sub)selections can be made. Is it possible to contact these members at short notice? Keeping personal data up to date requires a continuous investment. Data quickly become outdated and situations (regularly) change. To illustrate: yearly 3 to 5% of NVN members die, and a same amount of people or more become a member. On a yearly basis, many members change their therapy (from dialysis to transplantation, pre-emptive transplantation and from transplantation back to dialysis, et cetera).

### **Risk of research fatigue**

Researchers don't realize that they are not the only ones who approach the NVN for cooperation. We want to prevent research fatigue among our members and do our best to limit the amount of requests for participation to the various members categories on a yearly basis.

Still this is easier said than done. On the one hand we do not want to patronize our members, on the other hand it is sometimes hard to distinguish which research has priority over others. Therefore it is important to keep a research agenda to be able to determine which research projects are important to our members, directly or indirectly.

A first step towards such an agenda is the report: 'Leren over lijf en leven' (see ref. 4) that we issued together with the Nierstichting. Another example is the brochure 'Kwaliteit van zorg en onderzoek vanuit

patiënten- en cliëntenperspectief<sup>11</sup> (Quality in care and research from patient and client perspective), which offers criteria for relevant and non-relevant research. The first criterion being: Is the research relevant for patients and clients:

1. Will it improve the patients'/clients' health?
2. Does it take diversity into account?
3. Is it based on the patients'/clients' needs and questions?
4. Can the results be put to practice?

The brochure also contains questions about the quality of life, the quality of care, ethics and safety, information and communication and (pre)conditions for participation.

On the basis of these given criteria we will always carefully consider if a research project, in our opinion, meets these conditions. This means that we (as patient organization) want to be involved to a certain extend in research for which we approach our members. We get back to this later on in this chapter.

### **Research participation costs money**

The amount of time and costs a patient organization has to invest when participating in research is often underexposed. Researchers take it for granted that we recognize the importance of the research - which we do indeed - and consequently take for granted that we take the time and pay for the costs. In many cases we do not have the means.

<sup>11</sup> *Kwaliteit van zorg en onderzoek vanuit patiënten- en cliëntenperspectief*, VUmc, EMGO+, ZonMw, VSBFonds, Programma 'Patiëntenparticipatie in onderzoek, beleid en kwaliteit', 2012

The NVN is a subsidized association. In our yearly program of activities we determine how we spend this subsidy. The General Assembly approves this program. When we decide to participate in research, without being compensated, this will lay a burden on our program. Therefore the NVN finds it very reasonable that researchers budget the cost of patient participation in their research proposal<sup>12</sup>.

*To summarize the following points of attention: as 'research subject supplier' we should:*

- Always protect the privacy of our members;
- Make choices and set priorities since we cannot supply research subjects for all research;
- Ask a financial contribution for the recruitment of research subjects.

*To which the following remarks can be added:*

- The NVN wants to support all kidney patients and aims for a fair representation of the various groups of kidney patients. At the moment (end 2013) in the Netherlands there are:
  - 33 % of all dialysis patients is NVM member;
  - 17 % of all transplanted patients is NVN member;
  - 3 % of people with a chronic kidney disease without a kidney function replacement therapy is NVN member;
  - 9 % of all living kidney donors is NVN member.

In average 5 % of all patients with a specific affliction is member of a patient organization. So the NVN has a much higher participation rate (overall 11%).

- Often it takes extra effort to collect sufficient response to reach a representative member consultation. Calls for member consultations (NP online) or requests to participate in research are usually answered by only a part of the approached members. Letters or calls by mail or internet hardly render any response.

<sup>12</sup> This should be considered in proportion to the Nierstichting, who is the largest subsidier/sponsor of the NVN.

## 4.2 Patient association as informant

When as a patient association, we are approached to provide information, we should take several things into account.

### Even 'grey' data are valuable

The role of informant is close to that of the research subject. In this case information is provided on a more aggregated level, for instance seminar or conference records, reports on experiences with individual support given by the telephone service or the social counsellor of the NVN or the outcomes of the action report month during which experiences with the dialyses taxi can be reported (November 2013). Occasionally we organize a meeting, sometimes together with local kidney patient associations, where we submit certain questions to our members. This does not yield scientific data, but it gives insight that can be used for the research design and proposal. This type of information is called 'grey' data.

### Better ways of data collection and reporting render useful information

To be able to collect and provide this kind of data, we need to organize and report these meetings in such a way that they produce knowledge and information that can be placed in a personal as well as a social or organizational context. A good example is the discussion on whether or not organ donors should be paid for their donation. If this is properly debated within the NVN, it makes sure individual opinions are heard and at the same time it reveals the broader opinion that payment is not desirable, but an adequate cover of expenses is supported by (practically) everyone. This information can be used in research on how to stimulate organ donation.

*In summary we can distinguish the following points of attention: an informant should:*

- Make sure that member opinions and meetings are properly reported;
- Extend our cooperation with local associations to get a better picture of the opinions and experiences among our members.

*To which the following remarks can be added:*

- Gathered information should be better distributed. Sometimes our focus is too much on our members, as a result of the classical function of a member association (meeting each other). By joining the network of health care providers and researchers, we can better distribute or share information and third parties will recognize us more as informants.
- We should strive for more transparency about our data collection methods and we should dare to show more diversity and nuances in the way we communicate this information. As a member representative we tend to look for unambiguous views, leaving little room for nuance.

### 4.3 Patient association as advisor

When, as a patient association, we are approached for advise, there are several things to take into account.

As advisor we comment and give feedback during various stages of a research: in the design stage, the production of questionnaires, writing the report, drawing conclusions and formulating recommendations, communicating the outcomes to the target group, etc. These are all cases of active involvement and reflection on the various stages of the research process. This can take the form of formalized feedback groups, supervisory committees or steering groups.

#### **Knowledge and skills needed as advisor**

Occasionally as advisor we take a seat in a transcending program committee. This may concern a broader development trajectory or several research projects that share the same goal. Since this implies an umbrella role, we need to have the knowledge and skills that enable us to oversee a broader field.

#### **One interest: that of patients and clients**

It is vital to prevent personal or organizational interests play too big a role or become fuzzy and are not transparent. This applies to all stakeholders in the research.

*In summary, as advisor we must:*

- Have sufficient knowledge and skills to be able to perform the role of advisor. This applies to both members and employees of the NVN;
- Be transparent, meaning possible personal and organizational interests are obvious.

*To which the following remarks can be added:*

- To be able to perform as advisor, this person should have certain qualities and have authority to operate within that group. He should have this authority as well in the eyes of the party who wants to involve the NVN in the research, as among colleagues within the NVN.
- We should be able to describe the role of advisor and define his operational bandwidth and keep to these agreements.
- Our advice is only valuable if we can offer sufficient counterweight within the group where we act as advisor. Often enough there is only one patient representative among a group of clinicians or researchers.

#### 4.4 Patient associations as reviewer or commentator

When, as a patient association, we are approached to act as reviewer or commentator, there are several things to take into account.

##### Adequate knowledge and skills

As reviewer or commentator it is the job of the patient association to help judge research proposals and grant requests or comment on them during the decision taking process concerning a proposal. Therefore the reviewer should have adequate knowledge and skills to be able to judge scientific publications. Some members do, due to their scientific background. If not training might contribute. Anyhow, patient expertise is most valuable when the reviewer or commentator has adequate knowledge.

##### Prevent a conflict of interests

The NVN can never review or comment research proposals or grant requests, in which they are involved themselves. This involvement lies around the corner, since more and more researchers and institutes realize the importance of patient participation. Moreover there are many subjects which are so important to us, for instance because they are distinctive for the association or because they originate from our own members, that we would like to research them ourselves or have them researched.

*In summary, as reviewer we must:*

- Have adequate knowledge of and skills for the decision taking process of scientific research;
- Ensure that the patient perspective is always the starting point and gets adequate attention;
- Prevent conflicts of interest with research proposals and grant requests we want to submit ourselves.

*On top of that:*

- The reviewer must be able to fulfil his role without burden or consultation.
- The reviewer must guard his independence from all parties.

## 4.5 Patient association as co-researcher

The role of co-researcher can differ from research to research. A patient-partner is likely to be more personally involved in the research than an interviewer or questioner. The former being a full member of the research team, the latter being only involved in a part of the execution.

Schipper's research not only deals with the kind of knowledge patients have and contribute as research partners, it also deals with the development of their knowledge. Important to discover was that patients were able to keep their own perspective, as long as a couple of preconditions were met.

The most important precondition is being able to develop a shared communication context. Meaning: have in say in determining where, when and how the contact takes place, avoid using (too much) medical vocabulary, being able to develop a voice of one's own, being able to express oneself, etc. This will lead to mutual respect, patients' empowerment and researchers will get more insight.

Both patients and researchers need to be trained. They need to enter this development process together. It is important to take this into account when submitting a grant request. Finally the NVN should try and interest patients for this role of co-researcher and make sure all the preconditions are met.

*In summary, as co-researchers we must:*

- Invest in the relationship. The patient who acts as co-researcher should keep an open mind and dares to ask questions, both before and during the research process. Discuss what is expected of each other, dare to be pragmatic (indicate limits) and believe in one's own strength / power;
- Train the patient-partner that participates in the research;
- Train the researchers;
- Include additional costs in the grant request and convince the grant provider these costs must be compensated.

*In addition:*

- We must bring about a change of perspective, in which it is considered self-evident that the patient is important as co-researcher, unless one can properly argue why (he is) not.
- We must define in which type of research and what kind of (research) questions a patient can play a role as co-researcher.
- If we draw up a profile of the research partner and the researcher, it is clear which skills, background and responsibilities are needed for good cooperation.

## 4.6 Patient association as (co-)commissioner/initiator

Four types of commissioners can be distinguished:

### *Type 1: The commissioner as sponsor*

The commissioner has the financial means and can place a call or approach research institutes to hand in a proposal (and quotation). The contractor is directly accountable to the commissioner. The commissioner monitors the research project and makes sure it is carried out within the (quality) criteria agreed upon.

The NVN seldom takes the role of commissioner. We simply lack the financial means, neither do we have the infrastructure to judge research proposals and grant requests.

### *Type 2: The commissioner organizes the financing*

The commissioner does not have the means and therefore submits a proposal to a sponsor or fund, together with a selected research institute. The research institute will carry out the research commissioned by the NVN. The NVN is responsible for selecting the research institute, the quality of the proposal and the execution of the research within the determined quality criteria. The NVN sees to it the funds are spent on the research and is responsible and accountable for the relation with the sponsor/fund.

### *Type 3: Fellow commissioner*

Together with other patient associations, the NVN has acted as fellow commissioner of a research into the labour market position of people with a chronic affliction. This way we qualified for funds available for larger projects. The sponsor keeps a certain distance and together the patient organizations are responsible

for the research proposal and select the research institute, etc. Evidently it requires a specific approach by the various patient associations to reach a consensus, to act as one commissioner to the researchers and also to be accountable as one commissioner to the subsidiser. Compared to the first 2 types of commissioners, this type is somewhere in the middle.

### *Type 4: The commissioner looks for co-financing*

Finally the NVN can involve a third party in the research in order to realize co-financing. Third party candidates are, for instance, the Nierstichting or another fund or even the pharmaceutical industry. Examples of co-financing are some ZonMw projects (Kwaliteit van leven / Quality of life), life science and health projects and certain European projects.

### **Priority to research questions coming from members**

As commissioner the NVN want to focus primarily on research questions that originate directly from members. The research agenda that resulted from the research 'Leren over lijf en leven' (Learning about body and life) is partly used as guideline. Still it is possible new ideas or insights arise that call for additional research. Like in the case of the research project 'Mensen met matig tot ernstig verminderde nierfunctie in beeld' (People with mild to severe deteriorated kidney function portrayed). These people have no access to the so called pre-dialysis hospital facilities, but they have questions and limitations to which little attention is paid, as was signalled by members. We brought this to the attention of the VUmc and asked for a research proposal on this subject. The Nierstichting decided to fund this research project.

### **In-house research: member consultation**

Often the NVN lacks the financial means to be able to reward research requests. The Nierstichting, Zon Mw, European funds and the industry on the other hand do. At the most we can carry out in-house research, for instance in the form of member consultation by submitting a research question to our members. Although this is not considered scientific knowledge in the narrow sense of the word, it is a way of collecting information that can be used to formulate research questions, to put issues on the agenda or to serve as a research pilot, etc. To make sure a member consultation produces generic data, it is necessary to use methodologically correct questionnaires and to carry out a large enough sample survey, etc.

The NVN can organize a member consultation themselves (Nierpatiënten Perspectief online: [www.nponline.nl](http://www.nponline.nl)) or assign someone to do it for them. The NVN can also perform such a consultation for a third party, as long as the importance to their members is evident. In that case the other party will have to pay for the cost of such a consultation.

### **No data sale**

Some patient associations sell the use of their member data. They collect data themselves, buy them for instance from hospitals and make these data available for research. The NVN does not do this, because several other institutes already collect these (kinds of) data (like Nefrovisie does with Renine and Diavisie; and the Nederlandse Transplantatie Stichting (Dutch Transplant Foundation)). The NVN does collect, though, data necessary to be able to maintain the NVN quality standard for dialysis centres. At the moment the NVN is integrating this (form of) data collection into the nephrology quality system: Diavisie, to prevent extra administration and costs for the dialyses centres.

### **No scientific research**

The NVN does not have a (scientific) department, neither does it want to compete with the Nierstichting when it comes to initiating strictly scientific research. Moreover since the latter has set up her own scientific council. (see Introduction)

However, we consider it important as a patient association, that we are involved in drawing up a research agenda and in issuing research calls. At the moment the Nierstichting and the NVN are figuring out together how their respective roles of commissioner and stakeholder can best be tuned to one another in such situations.

#### *In summary, as (co-)commissioners we must:*

- Be committed to get recognition of patient associations as (co-)commissioners of research;
- Aim for a good cooperation between patient associations to come to joint research requests;
- Use patient perspective as starting point and pick up signals from members;
- Collect funds and offer support when necessary to be able to perform member consultations as professional as possible;
- Make sure a patient representative is involved in drawing up the research agenda and issuing calls.

# 5

## Summary and conclusions

**Since the middle of the former century patient participation has gained more and more attention. So far this has not led to a structural embedding in research policy. Not in the Netherlands, neither in Europe.**

Yet patient associations, researchers and policy makers see many possibilities and chances. They also recognize the added value of patient participation at all research levels and stages. Several instruments have become available, like the Participation ladder, the ZonMw patient participation manual and the Patient criteria brochure developed by Truus Teunissen. Moreover several studies have been executed, in which possible roles have been examined that patients might play in research.

Based on the resulting insights, the NVN wants to determine which position to take when it comes to patient participation in research. If patient associations want to make a valuable contribution to research - as research subject supplier, informant, advisor, reviewer, co-researcher or (co-) commissioner - a number of conditions must be met:

1. All parties involved **recognize** the importance of patient input, at all levels and in all stages of the research. They also agree the NVN can fulfil this role.
2. This implies that the NVN is **timely** involved in the research process. From the moment the research agenda is drawn up or calls for research proposals are issued, but also co-writing the conclusions, recommendations and implementation plans.
3. Patient representatives, on behalf of the NVN involved in the research as advisor or reviewer, are **proportionally represented**: so not just one patient among eight researchers or clinicians
4. The representatives form a **network**, that gives them a (virtual) platform to share their experiences during the research process.
5. This implies not only that the NVN can budget the **costs** of their contribution in research proposals or grant requests, it also means that the sponsor compensates these costs.
6. The NVN and its participants should be **independent**. The patient perspective should be the guiding principle.
7. Research including patient participation supposes **training of both patients and researchers**.

### The NVN:

1. Makes sure its total number of members is a fair **representation** of the different categories of kidney patients in the Netherlands.
2. Will **adequately** equip the patient representative.
3. Protects the **privacy** of those who participate in the research on its behalf.
4. Takes care of the **distribution** of the outcomes among kidney patients and other relevant stakeholders.
5. Is as transparent as possible about its role and involvement in research.
6. Can look **beyond its own borders** at other patient associations and cooperate in an international context when this is necessary or useful.

# 6

## Commentary

### **Patient participation in the broad sense of the word is probably better suited to social scientific research than fundamental scientific research, such as the biomedical causes or the development of the kidney disease.**

In cases where patient (associations) do contribute to this latter type of research, it is important to consider if there are no damaging factors for the patient. Also should be taken into account if there is ample attention for aspects that are important from a patient point of view. Take for instance restless legs. Many dialysis patients suffer from this phenomenon, but it is not considered very 'sexy' by researchers. This is also the case with co-morbidity that often occurs with elder people. Researchers need to rephrase their thesis or put their research question in a broader context. In fact the basic principle as described in paragraph 4.5 is the case here: it should be self-evident that a patient is important as co researcher, unless one can argue why this is not the case in this specific situation.

### **What next?**

Now that patient participation in research is thoroughly discussed in this document, it is clear in which direction we are headed. The NVN's next steps will be:

- We will share our policy intentions with various partners and other stakeholders, such as ZonMw, research institutes, other patient associations in the Netherlands as well as abroad, professional organizations, etc.  
Our aim is to reach more agreement, to realize the conditions and to take new or different points of view when necessary. We have already consulted the Nierstichting and this has led to new impulses to our cooperation in the research area.
- We will make sure that we stay in touch with our members, among others by means of systematic member consultations. That way we find out what is important to our members, what choices to make and how we can involve our members. Therefore we need an up to date database to be able to make data available and in order to be able to report them.
- We will develop an education and training program for NVN volunteers who want to contribute to research. In 2012 we organized a volunteer training day for the first time. It was a tremendous success and we will continue doing this.

- NVN cooperates with other patient associations and is an active member of the umbrella organisation Ieder(in) (a network organisation for people with a limitation or chronic disease) and a candidate member of the patient federation NPCF and the Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP) (Association of Cooperating Parent and Patient organizations). We are also active on an international level: in CEAPIR (European umbrella organization of kidney patient associations) and FedErg (European umbrella organization in creation for genetic kidney diseases). Active participation is continuously necessary to strengthen patient input on a broader level. Improvement and wider support will consequently strengthen our position and help us reach our goals.
- These steps take time and money to build up the necessary infrastructure. The NVN will finance part of this, but will also ask for a financial contribution.

# A

## Attachment 1 Participation ladder

Below a different view of the Participation ladder (different from the one on page 8) is displayed. This version expresses influence in a clinical setting instead of participation in research.

The model shows how the influence the professional can have and the influence the patient can have, act like communicating vessels.

It also shows the possible ways of putting patient participation into practice in various situations.





**Nierpatiënten Vereniging Nederland**

*Mailing address:*

P.O. Box 284, 1400 AG Bussum, The Netherlands

*Visiting address:*

Groot Hertoginnelaan 34, 1405 EE Bussum, The Netherlands

**T** +31 (0)35 691 21 28

**F** +31 (0)35 691 93 34

**E** [info@nvn.nl](mailto:info@nvn.nl)

**I** [www.nvn.nl](http://www.nvn.nl)

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