

# Patient participation in collective healthcare decision making: the Dutch model

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## Abstract

**Objective** To study whether the Dutch participation model is a good model of participation.

**Background** Patient participation is on the agenda, both on the individual and the collective level. In this study, we focus on the latter by looking at the Dutch model in which patient organizations are involved in many formal decision-making processes. This model can be described as neo-corporatist.

**Design** We did 52 interviews with actors in the healthcare field, 35 of which were interviews with representatives of patient organizations and 17 with actors that involved patient organizations in their decision making.

**Results** Dutch patient organizations have many opportunities to participate in formal healthcare decision making and, as a result, have become institutionalized. Although there were several examples identified in which patient organizations were able to influence decision making, patient organizations remain in a dependent position, which they try to overcome through professionalization.

**Discussion** Although this model of participation gives patient organizations many opportunities to participate, it also causes important tensions. Many organizations cannot cope with all the participation possibilities attributed to them. This participation abundance can therefore cause redistribution effects. Furthermore, their dependent position leads to the danger of being put to instrumental use. Moreover, professionalization causes tensions concerning empowerment possibilities and representativeness.

**Conclusion** Although the Dutch model tries to make patient organizations an equal party in healthcare decision making, this goal is not reached in practice. It is therefore important to study more closely which subjects patients can and should contribute to, and in what way.

## Introduction

In modern health care, there is a strong emphasis on patient centeredness.<sup>1-3</sup> Although the patient was central in health care in the past, the patient was a less active participant than now. Currently, an active role is attributed to patients on both the individual and collective levels. One of the aspects of patient-centred care on the individual level is the expectation that patients become a partner of healthcare professionals, rather than finding themselves in a paternalistic relationship with them.<sup>1,3-7</sup> Active participation of patients or healthcare users is also proposed for the collective level, even though representation of patients in healthcare decision making can be said to take place through elected representatives (parliament, government) or through advocacy by experts (healthcare professionals).<sup>8</sup> Patients are represented in decision making on various subjects, such as guideline development, research agenda setting, government policy making and quality projects in institutions.<sup>9-12</sup> The most important argument for active participation in healthcare decision making on the collective level is that the experiential knowledge of patients supposedly improves the quality of the decisions. There are also other arguments in favour of participation, such as better implementation chances for chosen policies, increased legitimacy and accountability, democratic decision making, patient empowerment and a more efficient and effective healthcare system.<sup>2,10,12-20</sup> But how should participation in healthcare decision making on the collective level be organized in practice?

There are three main ways to organize citizen participation. First, by inviting a representative group of average citizens to voice their opinion on a certain subject. Secondly, by asking a specific group of citizens, the ones that are affected by a certain decision, to participate. A third option is involving organized civil society groups. These different forms can be applied to the healthcare sector as well. In the Dutch case, there is a strong emphasis on the third option: patient organizations are often asked to represent the interests of patients in formal decision

making. This model can be described as neo-corporatist. The neo-corporatist model is often put opposite to a pluralist model of decision making in which interest groups try to influence decision making outside the system, especially by lobbying. In this article, we will study the patient participation approach in the Netherlands. We will answer the following research question: how does participation of organized patient groups in formal decision-making function in health care and what are the benefits and disadvantages of such a model? This question is interesting for two reasons. First, patient participation in healthcare decision making is on the agenda not only in the Netherlands but also internationally, and it is therefore important to learn more about effective ways to shape participation. Second, the Dutch case demonstrates how neo-corporatist decision-making functions in spheres other than that of socio-economic policy where the neo-corporatist model was first established.

Patients in the Netherlands have organized themselves at different levels. There are hundreds of disease-specific patient organizations, such as the breast cancer and epileptic associations. Individual patients can become members of these organizations. In the Netherlands, about half a million people have joined a disease-specific patient organization.<sup>21</sup> These disease-specific patient organizations are members of larger umbrella organizations, such as the Dutch Federation of Cancer patient organizations and the Federation of Rheumatism organizations. These organizations work together in even larger regional and national umbrella organizations, such as the Dutch Patient and Consumer Federation. In addition there are non-disease specific organizations catering to certain groups in society, such as organizations for elderly and psychiatric patients. Most of the work of patient organizations is carried out by volunteers. More than half of the disease-specific patient organizations work only with volunteers. Professionals support the work of the remaining disease-specific organizations and the umbrella organizations.<sup>21</sup> Most (70%) patient organizations are associations, which means that they

have an internal democratic structure in place, their members can give input and decide on the course of the organizations, mostly through general meetings. This is different in case of foundations, the organizational structure of the remainder of patient organizations, which do not have members but contributors which gives organizations more opportunities to decide on their course of action themselves.<sup>21</sup>

Interest groups depend on the opportunities the system gives them to influence decision making. For instance, they need acceptance from other actors as a legitimate party before they can become part of formal decision-making procedures. The opportunity structure of Dutch patient organizations has been described as one in which the other actors are very open towards them.<sup>22</sup> They are identified as a legitimate stakeholder and are asked to participate in many decision-making processes. This fits the neo-corporatist structure, or *poldermodel*, which can also be seen in other policy fields in the Netherlands.<sup>23</sup> The most important example is decision making on social economic policy in which several unions and employer organizations have been recognized by the Dutch government as legitimate partners in decision making. Corporatist decision-making structures exist in other sectors as well, for instance, the environmental movement is part of formal decision making on environmental policy.<sup>24</sup> The patient organization case, however, is quite distinctive, given that there is no formal selection of organizations that can participate. All patient organizations that wish to, may participate in decision-making processes. Patient organizations are recognized by the state and are called the third party in health care next to providers and insurers. Due to this recognition, patient organizations are increasingly asked to participate in decision-making processes. Moreover, patient organizations are heavily subsidized, enabling them to play this active role.<sup>25–27</sup> Additionally, patient organizations have the opportunity to influence decision making from the outside through lobbying, much like any interest group in a democratic state.

In other countries, the situation is different. Patients, healthcare consumers and disabled persons have organized themselves and tried to influence policy in varying degrees.<sup>28–35</sup> However, the invitation to participate in formal decision making seems less automatic than is the case in the Netherlands. Patient organizations are just one of the possible participants amongst others, such as the public, unorganized patients and carers (see for instance, Refs 17,36–40). Governments in other countries are also less supportive of patient organizations.<sup>28,30,34</sup>

In this study, we first describe the methods used to study the situation in the Netherlands. In the results section, we then describe: the participation opportunities, the influence patient organizations can exert on policy and the effects on patient organizations themselves. In the discussion, we focus on several dilemmas attached to this model. We will show that the opportunity structure is simultaneously both enabling and constraining.

## Methods

For the empirical part of our study, we conducted 52 interviews with different actors in the Dutch healthcare field. First, we interviewed representatives of patient organizations ( $n = 35$ ). We selected patient organizations from the different layers of the patient movement and aimed to have a mix in both size of the organization (large, medium and small organizations), and background of representatives (active volunteers and professional employees). By selecting organizations according to these different criteria, we tried to gain insight in differences between organizations' ability to participate and the dynamics between the different layers of the patient movement.

Additionally, we interviewed other actors in the Dutch healthcare field who have had experiences with patient participation in decision-making processes. These actors were identified through a document study<sup>41</sup> on which type of actors have contacts with patient organizations. We selected representatives of different actor groups: the ministry of health ( $n = 2$ ), supervisory bodies

( $n = 2$ ), healthcare providers ( $n = 2$ ), healthcare insurers ( $n = 3$ ), intermediary organizations<sup>1</sup> ( $n = 4$ ), research institutions ( $n = 2$ ), a health fund ( $n = 1$ ) and a government advisory body ( $n = 1$ ). An overview of the organizations we interviewed is given in Table 1.

We asked the respondents of patient organizations about their participation activities. How were they active, what were the experiences with these activities in terms of influence and what were the consequences for patient organizations? We asked the other respondents about their experiences in dealing with patient organizations in decision making. How were patient representatives given the opportunity to participate, were they able to participate, how did they contribute and in what way would these actors like to continue with patient participation in their future decision making?

The interviews were recorded and fully transcribed. In the analysis, we used the following analytical schemes: (i) what does the opportunity structure look like (what subjects allow for participation and how can organizations be active); (ii) what are the related experiences; (iii) what was the patient organization's input and influence on policy making; and (iv) what are the effects on patient organizations (what kind of conditions must they meet and how do they deal with their role)?

## Results

### Participation possibilities

Participation by patient organizations is not just a policy proposal; it is also put into practice. According to respondents ( $n = 17$ ), the time is right for patient organizations because it has become 'fashionable' to involve them:

These days it is not done to say that you find it a senseless development. (respondent Per Saldo)

<sup>1</sup>Organizations that function as intermediaries between different actors in health care, such as the Dutch Institute of Healthcare Improvement, which brings different healthcare institutions, professionals, patients and researchers together to work on the improvement of health care.

Thirty or so years ago, the situation was quite different. Our respondent from the breast cancer association recalls that volunteers who tried to provide peer support were not at all welcomed by the hospital staff. These days, however, the other parties involved in healthcare decision making, government, providers, insurers and researchers, give patient organizations many opportunities to participate. On the basis of our interviews, we can report the following participation possibilities.

Patient organizations are consulted by the ministry of Health Welfare and Sport, parliament, government supervisory and advisory bodies and municipalities. Some patient organizations also try to influence economic and social policy in addition to healthcare policy, by consulting with these ministries and contacts with MPs.

Participation by patient organizations can also influence healthcare providers. They contribute the patient perspective in guideline development groups and participate in the development of indicators used by the Dutch Healthcare Inspectorate. Some patient organizations develop their own quality criteria and attribute quality marks to providers who then provide care according to these criteria. Furthermore, they are involved in healthcare improvement projects and in the training of professionals. Smaller organizations sometimes focus more on representing the interests of individual members and intervene when they feel that one of their members is not receiving the appropriate care.

As the introduction of the Health Insurance Act, the activities of patient organizations have expanded. With the introduction of this act, a system of regulated competition was introduced in Dutch health care. In a system where insurers compete to provide insurance, patient organization-insurer contacts are potentially interesting for both parties. Patient organizations can negotiate collective contracts for their members, both on the content and price of insurance packages that are complementary to the basic package and can thus provide insurers with more clients. They also provide insurers with information for healthcare purchasing, which

**Table 1** Organizations interviewed

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NZa, the Dutch Healthcare Authority
IGZ, the Dutch Health Care Inspection
Slingeland, hospital
Atrium, hospital
Ministry of health welfare and Sport (2×)
De Friesland, health insurance company
Unive, health insurance company
Miletus, joint initiative of insurers to measure the experiences of patients
CKZ, centre that coordinates the development and implementation of the consumer quality index
CBO, Dutch Institute for Healthcare Improvement
STG, Dutch network for research, strategy development and healthcare innovation
RIVM, the National Institute for Public Health and the Environment
NIVEL, the Netherlands Institute for Health Services Research
MEE Nederland, national organization of MEE organizations (organizations that support people with a handicap or chronic illness)
Heart foundation
HOB, an organization that provides support to patient organizations
Per Saldo, organization of people with a healthcare budget to be spent on services of their choice
DVN, Dutch diabetes association
BVN, Dutch breast cancer association (2×)
Lymph node cancer association
VSN, Dutch association for muscular diseases
Pandora, organization of mental health clients
Alzheimer Netherlands
Dutch scoliosis association
Friedrich Wegener foundation, organization of patients with vasculitis
ME/ CVS Foundation, organization that deals with chronic fatigue syndrome
Parkinson patient association
ANBO, organization for people over 50
Child and Hospital
EVN, Dutch association for epileptics
Dutch Oscar Foundation, organization for patients suffering from sickle cell anaemia
Clientenbond, organization for mental health patients
LNKO National network of critical parents of handicapped children
Balans, organization for parents of ADHD patients
Pancreas association
Ypsilon, organization of family members of patients who suffer from psychosis
NFK, Dutch federation of cancer patient organizations
Federation complementary care
SHHV, foundation dealing with diseases in head heart and blood vessels
Federation of rheumatism organizations
CSO, central association of elderly organizations
CG-raad, chronically ill and handicapped council, national umbrella organization
Consumentenbond, national consumer organization
NPCF, Dutch patient and consumer federation, national umbrella organization
LOC, national organization of client councils of elderly institutions and home care
LSR, national organization of client councils of hospitals, and intramural care institutions
LPR, national organization of mental health client councils
Clientenbelang Utrecht, regional client umbrella organization
Zorgbelang Friesland, regional client umbrella organization

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insurers can use in their contract negotiations with healthcare providers. Healthcare insurers, healthcare providers and patients, have also worked together to develop and implement the Consumer Quality Index.<sup>2</sup>

Patient organizations are also active in decision making on health research in different ways. They can play an intermediary role between researchers and patients that are needed as research subjects. They are increasingly consulted in the development of research agendas and in research proposal assessment and supervisory committees.

The opportunity structure is one in which Dutch patient organizations can become part of institutionalized formal decision making on different levels, which affects the chosen strategy of influence. There is a strong focus on participation in formal decision-making processes and consultation, where the different parties in health care try to establish consensus. The importance of this is also recognized by the other parties in health care ( $n = 5$ ). An insurer claims:

So we [insurer and regional patient umbrella organization] are talking, we do not judge each other and we keep looking for possibilities to create an understanding for the other's point of view and to make improvements where possible. (respondent de Friesland)

In addition many patient organizations ( $n = 25$ ) report on lobbying activities outside the formal decision-making processes, mostly directed at the government and political parties. Most of this lobbying consists of writing letters and consultation; sometimes the media are also used. Mostly patient organizations are not looking for confrontation, however. Only one patient organization, the Diabetes association, had recently chosen a more oppositional strategy, trying to shake things up with harsh comments, e.g. saying that the quality of care is insufficient. Although other respondents identify diabetes care as a best practice that they would like to follow for other conditions, the Diabetes

association strategically argues that diabetes care leaves much to be desired. This new proactive strategy leads to a situation in which patient representatives vent their troubles without much nuance but according to our respondent this is part of a transition towards a situation with a stronger position of the patient.

I am well aware that patients reach a point where they just cry out what they're feeling, without worrying about the consequences. The same thing happened in communist revolutions – people were victimized there too, you know. But the point is, voicing one's feelings accomplished something. (respondent Diabetes Association)

Most patient organizations focus on the consensual mode of participation in formal decision-making arenas. When patient organizations focus on formal decision-making processes and abstract policy issues, they become part of the formal decision-making structure and become institutionalized. Through this institutionalization, they have the opportunity to act on all of the subjects mentioned. It has become an accepted practice to involve them, although most organizations want even more opportunities for participation and structural involvement ( $n = 26$ ). Many of the other actors wish to increase their contacts with patient organizations as well ( $n = 9$ ). Interestingly, at the same time, many patient organizations identify overload as a problem ( $n = 26$ ); they are asked to participate in so many cases that they cannot comply with all the requests.

You are swamped with stuff. It is too crazy for words, so many opportunities to participate. (respondent Pancreas association)

This difficulty in complying with all requests is intensified by the fact that patient organizations have difficulty in finding volunteers. They must deal with the fact that volunteers have to drop out regularly because of their illness. This leads to a situation in which a lot of work is carried out by a couple of active members.<sup>3</sup> So, even though organizations may want to do more, for practical reasons, this is not always possible.

<sup>2</sup>An instrument that measures patient experiences with health care.

<sup>3</sup>One respondent calculated that she spent 3250 h a year working for her organization on a volunteer basis.

They must look for (collective) solutions that increase their effectiveness as an organization.

Many patient organizations ( $n = 29$ ) therefore emphasized the need to work together to strengthen their position and to cope with all the participation opportunities given to them, although they acknowledged that they do not do this often enough in practice. Other parties ( $n = 5$ ) also emphasize that they prefer united patient organizations, because it is more convenient for them to talk to one central organization. The layered configuration of the patient movement in the Netherlands can arguably be seen as an organizational response to this situation. It offers patient organizations a chance to work together and be active on different levels of decision making:

Here's how we see it. Interests that all patients have in common, regardless of their condition, are taken up by the National Patient and Consumer Federation. Common interests of people with cancer are dealt with by the Dutch Federation of Cancer patient organizations. And when it concerns the specific interests of women with breast cancer, men with prostate cancer or whatever, then this disease specific organization becomes active. (respondent Dutch Federation of Cancer patient organizations)

However, this division of tasks is not easy. The members of the umbrella organizations do not always agree with the chosen course. And there is a difference of opinion on which activities member organizations should perform and which should be performed by umbrella organizations. Some respondents ( $n = 9$ ) feel that disease-specific organizations put too much emphasis on their individuality and the differences between groups of patients.

It surprises me that almost all patient organizations I have talked to (...) complain about a shortage of money and board members, but when you respond by telling them to work together, because then you need fewer people and can spend your money more efficiently: no. It is the uniqueness, you know: 'They will lose their uniqueness'. (respondent Federation of Complementary Care)

Another strategy used by patient organizations to cope with overload is prioritizing. Some see the need to delineate the issues that they feel

are important and should be pursued. By attaching criteria to their decision to participate or not ( $n = 21$ ), they can be selective and not pursue every subject that comes up.

### Influence

One of the goals of patient organizations is to influence decision making, which we saw in several cases. The HIV and the breast cancer associations, for example, were both able to change policy concerning medication distribution, while Per Saldo, an organization for people with a personal healthcare budget, was able to change the reimbursement criteria of health insurers. Several patient organizations ( $n = 5$ ) involved in a healthcare purchase project of an insurer were positive about this opportunity and claimed that their participation had led to positive outcomes, such as interdisciplinary teams and more information for patients. The association for muscular diseases is very successful as a driving force in research and treatment guidelines. The organization for children in hospitals created a quality mark, which insurers now take into account in their negotiations with hospitals, resulting in hospitals making changes to deliver care according to these criteria. The Diabetes association contacted the media to draw attention to unsafe blood tests, which led to an increased use of protocols. *Clientenbelang Utrecht*, a regional umbrella organization, signalled problems concerning dental care and now works together with the professional organization of dentists on guidelines for improvement. The Dutch Patient and Consumer Federation (NPCF) and the *Consumentenbond* made it easier for patients to file complaints and the NPCF also successfully lobbied for a healthcare consumer act, which is currently being developed.

Interestingly however, successful influence does not always result from participation in formal decision-making processes. The aforementioned changes of cancer and HIV drugs policy, attention for the diabetes protocols and the dentist guidelines, for example, all resulted from other strategies: using the media and lobbying.

Despite their successes, patient organizations question their ability to influence decision making in a general sense. They also report on examples of unsuccessful attempts to enhance policy outcomes ( $n = 18$ ). Negotiating collective contracts with insurers is an example of this:

The insurer says: 'we will do it like this', and that's it. (respondent HIV association)

Patient organizations attribute their lack of success to their dependent position ( $n = 25$ ), which is also recognized by other actors ( $n = 5$ ). Other actors in health policy making do not really need them, they can make their decisions and policy without them if they want to.

We [a regional patient umbrella organization] are often dependent on the goodwill of health care providers, municipalities or the insurer. They have to acknowledge the importance of involving the patient movement. If they don't they would get away with it. Because they are not obligated to make decisions together. They could do it without us. So it is terribly nice and kind and we are very glad with such a covenant [with the regional insurer] but it depends on goodwill. If the insurer would say: 'Enough. We won't do it anymore', there's nothing we can do about it. (respondent Zorgbelang Fryslan)

Moreover, because of their institutionalized and dependent position, it becomes difficult for patient organizations to follow their own course. They are in danger of being put to instrumental use as our respondents from both groups note ( $n = 17$ ). They are asked to contribute their opinions on items decided on by other parties, and it is questionable whether they can really influence the process. One respondent even feels that participation for many patient organizations has become a goal in itself:

There are quite a few organizations that find it marvelous to sit at the table with all these different parties; with the secretary of state for instance. I mean that is so pompous. (...) I think most of these organizations absolutely lose sight of what it is all about, and what life is about when you are unlucky enough to get some rotten disease anyway. (respondent Pandora)

Patient organizations are asked to contribute 'the patient perspective' to decision making.

Although this experiential knowledge base is not questioned by the different actors we interviewed, representatives of patient organizations do report on not being taken seriously in practice. Four of them directly link this to the difficulty of getting their experiential knowledge across:

When you've got one experiential expert in a guideline committee, you can say something a hundred times but that doesn't get acknowledged (...). But afterwards the outcome will be marked 'client approved'. So the question is, is it wise to participate in such a committee at all? (respondent Pandora)

The representativeness of input from patient organizations is occasionally questioned by other parties ( $n = 2$ ). According to our respondent from the organization in charge of the government website [kiesbeter.nl](http://kiesbeter.nl)<sup>4</sup>:

And what I am thinking about now is the difference between what you hear from patient organizations about what people want to know, (...) and what an average individual wants to know. (respondent RIVM)

That other actors also question their representativeness is suggested by the fact that organizations seeking the input of patients do not merely want to talk to representatives of patient organizations but want to consult unorganized patients as well. They consider additional participation methods ( $n = 10$ ), to learn more about what patients want or think about a subject.

#### Effects on patient organizations

Representatives of patient organizations report a positive effect of participation on the well-being of those who participate. Participation can be a means for patients to feel useful again, learn new things and increase their social capital ( $n = 8$ ). Some patients are no longer capable of work, but can be active in their patient organization:

<sup>4</sup>[kiesbeter.nl](http://kiesbeter.nl) is a government-funded website intended to assist patients in choosing their healthcare provider and their healthcare insurer.



When I think of a member of our board (...) he used to be a manager in a shop and he suffered from low self esteem because he was declared unfit to work, a very miserable situation. And then there you are; no job, pancreas patient (...). But that guy is now working here and he feels like somebody again. So it also serves a very important purpose for the volunteers. (respondent Pancreas association)

Professionalization is often claimed to be necessary to be able to participate, both by patient organizations themselves as by other actors in health care ( $n = 34$ ).

When the other party can rely on [your professionalism] (...) it becomes easier and easier to convince that other party. And that is how it works and we have that kind of position now. (respondent Per Saldo)

Professionalization programmes primarily target volunteers. Participation in formal structures is not an easy task and requires much time. According to our respondents, many volunteers lack the knowledge to be able to contribute. The first requirement, often mentioned, is that patient representatives are able to look beyond their own experiences. They further need to have strong negotiating skills or an understanding of medical or scientific knowledge, both of which can be used during discussions with other actors. Moreover, they must be able to express themselves and be heard. To be able to meet these requirements, volunteers receive training from their patient organization and/or organizations that organize patient participation in decision making. Despite claims that such professionalization is a prerequisite for participation, the whole practice raises questions concerning volunteers' actual representativeness once they have different knowledge and abilities than the average patient. Training of volunteers can contribute to their empowerment process, but part of the professionalization is also a search for 'the right volunteers' who already possess many skills mentioned above. Not everyone can thus become active in a patient organization, which diminishes the empowerment potential for certain groups of patients.

The empowerment effect cannot occur at all if patient organizations decide to employ healthy

professional workers. Yet, it is claimed that active volunteers with experiential knowledge are not enough for patient organizations to be successful. Although they have the experiential knowledge that is continuously emphasized as imperative, respondents point out the need for professional employees who have the knowledge to influence decision making and to safeguard the continuity of the organization ( $n = 25$ ). To be able to participate, skills are necessary that volunteers just do not have:

Too many interests are at stake and it becomes too serious to ask that from a volunteer. (respondent Child and Hospital)

Working with professionals further increases the aforementioned concerns regarding representativeness. Although many respondents acknowledge that this professionalization process is difficult, only a few respondents ( $n = 3$ ) resisted the professionalization idea and the pressure to become more active in formal decision-making processes.

## Discussion

One characteristic of neo-corporatism is that actors need to be recognized by the government to become part of the formal decision-making structure. Government therefore decides who is in and who is out.<sup>42-44</sup> In this case, we find a similar situation, though shaped differently.<sup>5</sup> Patient organizations have become part of the decision-making structure, but there are too many opportunities for participation and many organizations simply cannot cope with the demand. Although the opportunity structure does not deny access, it can still inhibit participation because it demands so much time and energy that many organizations fail to meet expectations. Some organizations are unable to have a consistent presence simply because of decreases in population; lung cancer is one example. Organizations representing patients

<sup>5</sup>Despite market reforms, introduced in 2006, the Dutch government still plays a very important role in healthcare politics. It has promoted patient organizations since the 1980s and has continued to do so ever since.

with less debilitating diseases may be much better at participating. Furthermore, some patient organizations, mostly those representing large patient groups, have the funds to professionalize, whereas others do not. As was reported in the more pluralistic model in the USA where patient organizations lobby for research into their particular disease,<sup>45-47</sup> this could lead to redistribution effects, also in the neo-corporatist structure of the Netherlands.

In a neo-corporatist structure, influence is also an issue. Participants are seeking consensus and must often be satisfied with less-than-ideal outcomes.<sup>42</sup> This problem is intensified because of the difficult fit between patient organizations and the formal decision-making structure. Patient organizations have difficulty in contributing their perspective and have little bargaining power to support their position. However, for a neo-corporatist structure to work, some kind of power symmetry between the involved parties is necessary.<sup>48</sup> Given the fact that patient organizations do not have an equally powerful position as the other longer-established powerful parties in health care, this case shows that participation does not equal influence. The position of patient organizations is legitimized by the contribution of their experiential knowledge. However, part of the difficulty is that this knowledge alone is insufficient. They also need the capacities to get their points across in decision-making procedures with professional partners who have a strong knowledge base of their own. Experiential knowledge seems to be valued less than the evidence-based knowledge of healthcare professionals. Additionally, patient organizations have little power to force other parties to listen to them. Because they must first seek legitimacy, patient organizations begin in a dependent position, which leads to the possibility that their inclusion will merely be instrumental. Patients are asked to participate but cannot really influence the process, while the other parties can point to their presence at the table and say that they support the decisions made. Harrison and Mort<sup>49</sup> refer to this as *playing the user card*. If patients refuse to cooperate or have a different opinion, their

opinion can easily be overridden and the other parties can continue without them.<sup>6</sup> This dependent position also makes it difficult for patient organizations to follow their own course; they seem to follow the agenda of other parties instead. It is not clear whether participation in formal decision making accomplishes more than trying to influence decisions from the outside. Indeed, several of the successful examples of patient organizations influencing health policy came from lobbying (see also Ref. 50).<sup>7</sup> The question therefore becomes whether this neo-corporatist model is a good model to influence decision making or if patient organizations should look for other ways to influence policy making.

Finally, the effects on the organizations themselves raise some problems. An important issue often mentioned in the literature is the representativeness and accountability of interest groups.<sup>51,52</sup> Participating in formal decision making is not an easy task and the reaction of patient organizations has been to professionalize. Tasks previously carried out by volunteers are now performed by professional workers, or by trained, mostly highly educated, volunteers (see also Refs 11, 50, 53, 54). Although professionalization is necessary to be able to contribute, it simultaneously creates distance between active participants and those they claim to represent. Professional employees and professional volunteers have different knowledge that could colour their input and that brings the issue of representativeness to the fore. The experiential knowledge patients were originally asked to contribute could paradoxically disappear in the background this way. Professionalized interest groups diminish the democratic potential of citizen groups.<sup>55</sup> Whereas citizen groups with strong roots in society can strengthen democracy because ordinary people are mobilized, can participate, gain skills and interact with different

<sup>6</sup>Harrison and Mort studied patient panels in the NHS, indicating that the danger of instrumental use is not limited to formal decision-making structures as discussed here.

<sup>7</sup>It is likely, however, that patient organizations can be successful in such lobbies in the Netherlands, partly as a result of their acknowledged position.

people,<sup>55,56</sup> professional groups often lack such ties and therefore their contribution to democracy can be questioned. When patient organizations focus on their professionalization too much, they move away from the people they represent, which negatively affects their democratic potential. Another side-effect of the continuous emphasis on professionalization and the search for the 'right volunteers' is that the empowerment effect<sup>57</sup> that patient organizations can have for their members is in danger of disappearing.

We feel the results of this study are not relevant only to the Dutch case, as a similar role for patient organizations is being developed or considered in other countries.<sup>28,33,35,58,59</sup> We argue that the opportunity structure created in the Netherlands to make patient organizations an equal third party in health care does not accomplish this goal in practice. It is important to look critically at this mode of participation and its effects. The problem of the number of participation possibilities is that there are too many, not too few. It is therefore important to investigate further which subjects lend themselves to patient participation and which ones do not. The idea that patients should become an equal third party in every decision-making process concerning health care is not feasible in practice nor is it desirable when we look at the effects described in this study. It is also important to study other influence strategies of patient organizations such as lobbying or media utilization. Forms of participation that rely on individual patients, such as focus groups, shadowing and training by patients,<sup>57,60,61</sup> which have the advantage that they demand less of participants and are able to stay close to patient experiences, should also be considered.

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