

**MACHIAVELLI IN CIVIL SOCIETY:  
PATIENT ORGANIZATIONS IN THE NETHERLANDS**

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# **MACHIAVELLI IN CIVIL SOCIETY: PATIENT ORGANIZATIONS IN THE NETHERLANDS**

## **1. Introduction**

In 1513 Niccolò Machiavelli wrote his famous pamphlet *The Prince*, dedicated to “the Magnificent Lorenzo di Piero de' Medici.” *The Prince* was to become a classical text on the shady sides of politics. Machiavelli discussed how princes should behave when they came to power in a new principedom. According to Machiavelli they should bring their new principedom to order and obedience, and they should not be afraid of a reputation for cruelty. Setting a few signal examples might be the right method to claim obedience from the populace: “[T]he usurper should make haste to inflict what injuries he must, at a stroke, that he may not have to renew them daily, but be enabled by their discontinuance to reassure men’s minds, and afterwards win them over by benefits.” Cities accustomed to freedom for their citizens had better be destroyed altogether, because their inhabitants could never be trusted to accept the prince’s authority. In states and cities that had been ruled by princes before, it seemed paramount that the new prince should kill his predecessor and his entire family, so as to make sure that his new subjects should not seek recourse by the descendants of the old prince. Machiavelli did not have any moral scruples. The ultimate end – order in the state – justified almost all means (Machiavelli 1992).

Although *The Prince* is still worth reading for aspiring politicians, the days of Machiavelli are over. Today’s politicians are surrounded by moral and legal rules, which hinder their capacity to rule effectively. Politicians cannot kill or otherwise silence their opponents. They cannot scare them by signal examples of cruelty. They have to abide by constitutional rules regarding the freedom of speech. They are faced with an inconvenient prohibition of arbitrary decrees: every rule has to be formally endorsed by parliament. They have to accept the existence of checks and balances, which entails among other things that they sometimes have to submit to the authority of an independent court. They cannot rule forever unless they are regularly re-elected by the populace and so forth.

However, there seems to be one area in which politicians can still manoeuvre as they see fit. Politicians can interfere in civil society, almost any way they want, without meeting legal or constitutional obstacles. This, at least, is what we want to demonstrate in this paper, using the example of the Dutch patient movement. In section 2 we will describe Dutch patient

organizations. For readers who are used to doom and gloom stories about the decline of civil society (inspired by Robert Putnam), this section may read as a story full of glad tidings. In section 3 we will describe the government's interference with patient organizations. This section could be subtitled 'Machiavelli in civil society'. We will describe governmental intentions as they were laid out in white papers and other policy documents and then describe what happened in the real world of patient organizations. (Readers who are familiar with Habermas' theory might read section 2 as a description of the 'life world' and section 3 as the story of its colonization by the 'systems world'.) In section 4 we will confront both perspectives and discuss governmental interference with civil society. What should we think of this type of high-handed interference in civil society? What does it mean for organizations that are subjected to such interference? Do they have any defence against Machiavellian scheming and -plotting? We will draw some conclusions concerning moral norms for politicians and governments who consider interference in civil society.

The empirical findings are based on our research into patient organizations in the Netherlands. We studied the websites of 386 patient organizations and policy documents regarding patient organizations from 1974 till the present. In addition we interviewed 25 representatives of patient organizations.

## **2. Patient organizations**

The central message of Robert Putnam's *Bowling Alone* (Putnam 2000) was twofold.

1. Civil society – boy scouts, church choirs, soccer clubs and what have you – can work wonders. Citizens in a state with a blooming civil society may enjoy economic prosperity, good governance and better health.
2. Civil society is in decline. People no longer join traditional organizations (parent teacher associations, boy scouts, trade unions and political parties) and they do not seem to found new organizations either. Instead they seem to be preoccupied with work, their own family and the television.

In the closing chapter of his book Putnam challenges his readers to reinvent civil society, and to create new, modern organizations, that could have the beneficial effects that traditional organizations used to accomplish in the past. The founders of Dutch patient organizations seem to have had presentiments about this message. We studied the websites of 386 patient organizations. Not all organizations disclosed their founding history on their website, but many (154 organizations) did. A large number of patient organizations have been

created after 1980, hence during the period in which civil society was supposedly withering away.

Founding period	Number of organizations	Percentage
Up to 1980	32	20,8
1981 - 1990	50	32,5
1991 - present	72	46,7
Total:	154	100

*Table Founding year patient organizations in the Netherlands*

Moreover, many patient organizations have a typically modern history, that is, they have origins which could not have been invented before the Second World War, let alone in the nineteenth century. Some organizations were founded as a follow up after interviews with patients or their relatives had been published in widely read magazines. Others seem to have been the direct result of television programmes. The founders of the Missing Link Foundation (an organization for parents of children with the so-called Dr. de Rijk syndrome, a genetically based neurological condition) put their history on their website:

“The history of our organization started on august 30<sup>th</sup> 1995, the day that we, parents of Sebastiaan made headlines in the local press. The article was the result of the efforts of a social worker, whom we had met in St Ignatius hospital in Breda. She found Sebastiaan’s history – curing an unknown disease – fascinating. She called the local newspaper [...], and then SBS6 [a broadcast company, MT and HvdB] called [...]. After that, we were approached by Ivo Niehe Productions. We had a whole camera team that came by for the television show. [...] As a result of that show, two new patients were identified and cured subsequently. And then the doctor said that we as parents had done an impressive job, and she suggested that we should form an association of some kind or other.”

The origins of the Strugglers organization (an organization of grown ups who were abused as a child, founded in 1993) could also be traced back to a television programme. The website tells us:

“When the IKON [a television company] broadcasted this material, Hilversum [the city from which television is broadcasted in the Netherlands] was bombarded with phone calls from viewers, who recognized themselves in the stories and the images. Many of them were happy to learn that they were not the only ones, feeling the way they did; and it seemed to make sense that they had a strong urge to meet fellow sufferers. [A doctor] suggested that the IKON should invite viewers to come and meet in Hilversum, on a special day. [...] About 60 people showed up. [Under the professional guidance of the doctor] a preliminary board was

formed, which was supposed to find out what the association-to-be could mean for its members and for society at large.”

Putnam acknowledges that his decline of civil society thesis did not apply to so-called identity groups, such as patient organizations. Identity groups (self-help groups and the like) are still being founded and do manage to attract new members. However, according to Putnam these groups do not deliver the positive goods that were so amply provided by organizations such as the boy scouts and the Parent Teacher Associations. Identity groups are supposedly inward looking. They are about forming ties with similar people within one’s group. They are not about reaching out to other groups, they are not about bridging, that is: meeting and forming ties with different people, confronting your own point of view with other opinions.

Hooghe (2002) questions this negative verdict. He argues that all associations are simply communities of the like minded, be they boy scouts, church choirs or identity groups. We agree with Hooghe. In certain ways all associations are alike. They must all have an executive board, they must keep their administration in order, they must collect contributions and organize activities. If the current secretary or treasurer wants to step down, they have to find a successor. They have to find new members to keep the organization alive. In this day and age many associations strive for web presence, hence they have to find people who are willing and able to build and maintain a website. These are typically competences that one may need as a citizen and with regard to all these competences patient organizations and other identity groups (such as associations for gays or lesbians, or organizations for ethnic minority groups) do not differ from soccer clubs, gardeners clubs or amateurs orchestras. All of these organizations can be considered schools for democracy and citizenship. Many patient organizations even offer their active members courses to become better chairmen or treasurers. One of our interviewees, an active member of the Parkinson Association explained it as follows:

“You see, what we do here has nothing to do with our being sick. The contacts with fellow sufferers are very direct but here you are busy with thinking of things. So that has not much to do with your being sick and that is kind of nice.” (interview 27-1-2006)

Moreover, our research suggests that patient organizations can provide both bonding and bridging social capital. For many patient organizations their main reason for being is bonding, organizing contact between fellow sufferers. For some patients who are suffering

from a serious chronic disease, bonding social capital may be the only social capital they can acquire. One cannot easily join a sports club if one is suffering from a serious, invalidating disease. Joining a patient organization may be a way to take people out of their otherwise isolated lives (cf. also Hooghe 2002). The positive effects for these members can be very large. The chairman of the Pancreas Association talked about the way this can give meaning to a patient's life:

“When I think of a member of the board, he is very sick (...) He used to be a manager in a bicycle shop and he had low self esteem, was declared unfit to work; a very miserable situation. And there you are: no job, pancreas patient. I was able to help him enormously. He was so grateful that he started to work here. Now, that man works here on all kinds of things, he feels like someone again. So it also has a very strong purpose for volunteers and that is wonderful, he is someone again. You take people out of something.” (interview 20-2-2006)

An active member of the Cliëntenbond, an organization for psychiatric patients, told his life story:

“My supervisor [in college] said: make sure you stay out of psychiatry because then you can kiss your career goodbye. And that is what I did [when I was in college]. But then I got my diploma and realistically speaking: I could not work. Eventually I have been admitted (in a psychiatric institution) and then I said about my study: It was nice, but tough luck. The labour exchange bureau couldn't help me. And then I said well then, I will stay in the volunteer business on behalf of the mental health care clients, then at least I am doing something useful and that is better than sorting peas.”(interview 25-1-2006)

Patients who do not lead isolated lives might still rather join a patient organization than a soccer club. A patient who has to undergo kidney dialysis twice or thrice a week (each dialysis taking half a day, followed by a few hours recuperation), who wants to spend time with his family, take care of his children and who desperately wants to hang on to his job, does not have much time left for a diverting hobby. It seems excusable and understandable that he may spend what little time and energy he has left on an association that can provide him with information about how to make his life a little easier. So yes, patient organizations are about bonding, and for some patients having bonding social capital is simply better than not having social capital at all.

On the other hand many patient organizations offer their members opportunities to come into contact with people who are not fellow sufferers. Many patient organizations were (like the two examples described earlier) founded at the behest of medical professionals. Members of patient associations meet with medical professionals (physicians, researchers and

nurses) who come to tell them about state of the art treatment, or new lines of research during, for example, the annual meeting of the members of the association, or during a special conference, organized by the association. Many patient organizations have a medical advisory board, where patient members can meet with medical professionals on a more frequent basis. Nowadays medical professional organizations, which develop guidelines and protocols for the diagnosis and treatment of particular diseases, invite members of patient organizations to join working groups or standing committees that develop guidelines ([www.cbo.nl](http://www.cbo.nl), [www.trimbos.nl](http://www.trimbos.nl)). Our interviewees indicated that membership of such a committee had been a rewarding experience. One of them said:

“I am now in the group that has to upgrade the guideline (...) and I notice that I am getting better at it. Like ... it used to be that what I said didn't come across, because it was just an opinion. But now I try to find as much literature as possible, I am going to take a course in searching medical stuff, so I will really be able to find my way about. So I can say, this is what we want. Let's see, has anything ever been written about that?” (interview 7-2-2006)

And another interviewee told us:

“Our experience is that this works very well, participation in a guideline group like that. [...] It shows that doctors are willing to be open about their work. This is something that [not every organization] understands, that doctors are sometimes willing to do what's right, that they are not just covering for each other all the time. Because you see them at a vulnerable moment, [when different competing specialists have to discuss what the right treatment should be]. And they are going to decide, together, what is best for the patient. And I am sort of a guardian of the patient's interest. And they allow me to be that.” (interview 5-1-2006)

Other organizations engage in the world of medical research (Caron Flinterman 2005; Klop e.a. 2004). During our research thirty websites of patient organizations mentioned activities in this area. Organizations financed and supported special chairs, they made calls for research proposals, and they advised their members when and where to participate in medical research. One of our interviewees told us:

“We put a whole research into motion. We wrote to all the patients. A good scientific research, under the wings of Maastricht University. We always said: we must not do this ourselves. We must make sure that somebody else, say, a university, is behind it. But it was our research, our design, they just corrected some mistakes. We put it in the computer ourselves. The husband of one of our patients turned out to be a statistician. So, that way, we got a lot of work done.” (interview 9-3-2006)

A representative of Balans, an organization of parents with a hyperactive child (suffering from Attention Deficit Hyperactivity Disorder, ADHD), explained how she managed to get

invited to serve on a committee of the Health Council (an important advisory council in the Netherlands).

“They [the Health Council] had done a report on dyslexia, and then we have been lobbying big time, to have them do one about ADHD as well. There is always debate, on whether it’s actually the upbringing that causes it and all that. And then there’s been this committee, they had already thought about it, but then they actually formed a committee, and they wrote a report on ADHD: it is such and such affliction, and this is the treatment, and here’s the literature. And then you have the facts to back up your argument, don’t you? And I got to participate in that committee. And that [...] never happened before. For it’s not like I got a college degree or something and it’s a scientific council. I asked if I could attend the meetings. And at first they said I couldn’t and I got very angry [...] and then I said to the chairman of the committee [...] I worked so hard to make sure this committee would be there, and now it’s there, everybody is on it and I’m not! And somehow I got invited after all.

But it’s been a really interesting project for me. You get to meet with the high and mighty, and it’s very interesting to see how all this works. Also for your relations and all.” (interview 12-1-2006)

Active members of patient organizations also meet with health insurance companies and local government authorities. Lastly, the networks of active members of patient organizations are enlarged by the fact that these patient organizations are part of a broader movement. Patient organizations form coalitions with other patient organizations, more or less formalized in national and regional umbrella organizations. Members of patient organizations meet other people in conferences, seminars, board meetings and other activities, organized by their umbrella organizations.

### **3. Enter the government**

Researchers interested in health care policy in the Netherlands usually start their analysis of health care policy in 1974, when the then junior minister of health produced a large white paper on the future of health care in the Netherlands (before 1974 health care policy had been a rather undeveloped area). We will follow this delimitation approach and discuss relevant policy documents since 1974. We will indicate what the government had in mind for patient organizations and what happened with these organizations when the policy statement was issued.

#### *1. Encouraging participation in institutions*



The 1974 white paper was the first government document in which the position of the patient in the health care system was officially discussed. The government had noticed that health care had become large scale, bureaucratic, high tech and professionalized. It seemed possible that patients would get lost in large, bureaucratic hospitals and other institutions. Therefore it was deemed necessary that patients would henceforth participate in decision-making processes in care institutions (Stüssgen 1997).

In the second half of the seventies councils of residents and patients were set up, first and foremost in psychiatric hospitals.

## *2. Creating regional platforms*

In 1981 another white paper was published, entitled *Patient Policy* (TK 16771, nr. 1-2). Junior minister Veder-Smit argued that users of care should have a say in the provision of care, in all sorts of institutions, at all sorts of levels. However, it did not seem easy to realize that, because patients did not seem to be organized in the right way. There were no regional organizations with a general interest in health care policy. There were a lot of disease-specific organizations, but their members were often too sick to have much time for civic activities in planning councils. Even where their health did not present an obstacle to participation, they showed a sad lack of interest in matters of planning and policy. In many cases, policy making was not even mentioned in the articles of association of patient organizations. Moreover, different organizations did not always work together, which might have something to do with a lack of money. Hence the junior minister announced that she would ask regional authorities to spend some money on patient organizations, so as to help them create and maintain regional platforms, which could collect and deliver expertise and knowledge regarding policy issues.

In the first half of the eighties regional platforms for patients and health care consumers were created everywhere in the country, financed with regional governments' money.

## *3. Creating a national platform*

In the same 1981 document (TK 16771, nr. 2) the junior minister announced that she would like to see a national platform for patients and health consumers, which might act and speak on behalf of patients. She did not intend to prescribe the structure of such a platform in great detail, but she made it quite clear that she did not fancy mixed organizations, which had organized the interests of both patients and health care professionals. In her opinion patients

and health professionals had “structural intrinsically conflicting interests”. Nor was she a great friend of disease specific organizations, because these were all in all far too sympathetic towards medical professionals. Apparently the members of disease specific organizations considered health professionals as their brothers in arms, in a common fight against disease, whereas she, the junior minister, very much preferred critical organizations who were eager to discuss abuses and wrongs in the health care system. She also liked the two then existing consumer organizations in the Netherlands. True, they did not quite represent patients (after all they worked on behalf of consumers of food, furniture, household equipments, cars, bikes and all sorts of other consumer goods, besides health care provisions), but unlike the disease specific organizations, they showed the right critical attitude.

If some kind of national platform for patients and health consumers were to be formed, the junior minister would ask certain members of the platform to serve in important advisory councils, such as the National Council for Public Health.

In 1983 a national platform for patients and consumers (the LPCP) was founded. It consisted of the two consumer organizations that had been so highly praised by the junior minister, a few general organizations, who addressed certain forms of abuse in the health care system, and the Cliëntenbond, an organization of psychiatric patients widely known for its critical attitude towards medical professionals, psychiatrists in particular. The LPCP was awarded three seats in the National Council for Public Health. It was also asked to participate in certain bodies of the health council and in an official committee, which dealt with postgraduate schooling in medicine.

#### *4. Creating a new national platform*

In 1988 junior minister Dees published a follow up white paper on Patients Policy (TK 16771 nr. 31). Dees emphasizes that patients should be seen as consumers of health care provisions, to be paid by themselves (obviously via health insurance). As consumers they should have legal rights, financial support, and they should participate in all sorts of decision making bodies. In another white paper, published in 1992, the government announced that this kind of extensive participation in decision making bodies required a patient movement that would be organized more clearly and more consistently (Stüssgen 1997). The government needed an umbrella organization that would represent a larger part of the patient movement than the LPCP.

This wish was granted almost immediately. In 1992 the National Patients and Consumer Federation (NPCF), a broader federation of coalitions of patient organizations, replaced the LPCP (TK 22702 nr. 11).

### *5. Creating a professional movement*

In several policy documents the government emphasized that patient organizations should be 'professionalised'. What the government meant by professionalisation was not always explained, but overall, one got the impression that organizations should have a proper administration, they ought to formulate policy goals, they ought to evaluate whether these goals were accomplished (according to the famous plan-do-check-act cycle) and they ought to be able to participate in the decision making bodies that the government wanted to open up for them. This entailed that they should have highly qualified volunteers, or that they should hire educated personnel. This would cost money, and membership subscriptions might not be enough to cover that kind of expenses. Hence, the government created a subsidy fund in 1996 in order to accommodate the process of professionalisation (TK 27807 nr. 3).

In 2002 the patient fund was evaluated. The government concluded that the process of professionalisation had indeed taken place according to plan (TK 27807 nr. 3).

### *6. Creating an efficient movement*

Granting subsidy entailed detailed supervision on how the money was spent. In October 2000 health care minister Borst wrote a letter to parliament in which she announced: "Based on the impression that there is a certain overlap in the tasks and activities of the National Patients and Consumer Platform, the Council for the disabled, and the Union for the organizations of the chronically ill, I have asked Price Waterhouse Coopers [an accountants and consultancy firm] to investigate how the cooperation between these three organizations is getting shape, to see whether there is indeed overlap or perhaps white spots [areas getting too little attention]." (TK27400 XVI, nr. 8)

Before the investigation was really carried out the Council for the disabled and the Union for the organizations of the chronically ill put two and two together and decided to merge.

### *7. Encouraging participation in the new health care system*

In 2006 the Dutch government introduced a new health care insurance system, based on managed competition. Every citizen has to buy health insurance. People are free to choose an

insurer. Insurers have to strike deals with hospitals and general practitioners about the price and quality of care. Hence individual patients ought to be able to perform a two level judgment procedure: which insurer will give me what type of care, in which hospital? Who are the right doctors and did the right insurer contract them? This is a complex task, and the government thought that intermediary bodies, such as trade unions or employers, would strike collective bargains: all employees of such and such firm can have relatively cheap health insurance with insurer so and so. A similar intermediary task was laid out for patient organizations. The new system allowed and expected them to strike deals on behalf of, say, patients with a heart condition, diabetic patients, or asthmatic patients.

In January of 2006 the National Patients and Consumer Federation reported 15 such contracts of patient organizations with health insurers. In January 2007 this number had increased to 40 ([www.npcf.nl](http://www.npcf.nl)). When we did our website research the new system had only just been introduced. However, we already found signs that patient organizations were trying to live up to these expectations. 22 websites referred to health insurance companies. A few organizations had already closed a deal on behalf of their members, to realize a collective contract with extra care for their disease. Others provided information about insurers, and still others mentioned that they had tried to strike deals with insurers but had not succeeded, because the insurers did not find them an ‘interesting group’, probably from a business perspective.

#### *8. Creating an accountable movement*

The transition from the old to the new insurance system had a long history. During this history the position of the patient movement was discussed from time to time. In 2001 the government produced another white paper (*Choosing with Care*), in which the future of the patient movement was discussed (TK 27 807 nr. 2). The government decided that the regional platforms, created at the behest of previous governments, should be allowed to stay. However, they would have to develop plans on how to include disease-specific organizations. Also, they would have to be able to speak with one voice despite the fact that they represented a variety of organizations. Moreover, patient organizations should search for the right balance between interest representation at the regional and at the national level. According to the government, during the period of transition from the old to the new insurance system, it would be very important for the patient movement to present a united front. The minister wrote: “If the patient and consumer movement wants to play a meaningful role in the health care field, it is

paramount that it should present a united front with respect to major issues such as the insurance system [...]. In the next few months we will consult with the organizations involved, so as to accomplish that this process proceeds with the required speed.” The subsidy system will be transformed into a proper fee-for-service system. Organizations get subsidies if they can make clear what they plan to do with the money, and there will be a limited list of functions, products and services, which are eligible for subsidy. “Thus it will become possible to distinguish between money spent on interest representation, on the provision of reliable, state of the art information, on counselling and help, on the organization of purchasing power, and on the mobilization of bargaining power.”

Most patient organizations seem to resign to the new procedures. They merge when they are asked to do so, they present a united front and they perform the administrative tasks, which are necessary to apply for subsidy money. Our interviewee from the Cliëntenbond said:

“The Cliëntenbond has always said: we have kind of an umbrella function and we want to be paid as such. And in the past the health department went along with that. Last year we had a quarter of million and this year we have to make do with 60 000. They have classified us as a disease specific organization, that’s the big difference. But hey, that is the wishes of the ladies and gentlemen in The Hague, you can’t do much about it.”(interview 25-1-2006)

The only interviewee who was negative about governmental interference was the chairperson of the Oscar association, for patients with a genetic blood disease. She was an immigrant from the UK and she declared:

“I would never apply for money in the Netherlands, never. I have seen it, you really try to give shape to the representation of patients, to do the things they need, but you confront a bureaucracy in the Netherlands [...] It’s not normal, really, it is not normal. Look, every country’s got something, there is red tape in England too, but here ...!” (interview 28-2-2006)

### *9. Encouraging participation in guideline development*

In 1995 the minister of Health stated that she would “support a creative and active contribution of patient/consumer organizations in the advancement of efficacy on the meso- and micro-level. On the basis of their experiential knowledge they have to obtain their place in the guideline movement. This entails wanting and daring to carry joint responsibility for the content and application of guidelines from the NHG (Dutch College of General Practitioners), CBO (Dutch Institute for Healthcare Improvement), scientific associations and others, insofar as these guidelines are important from the patient’s perspective” (TK 24126 nr. 9: p.20).

By the end of the 20<sup>th</sup> century representatives of patient organizations started participating in guideline development. By now guideline development organizations have made it their policy to let patient representatives participate in the development process, for instance in guideline development groups ([www.cbo.nl](http://www.cbo.nl), [www.trimbos.nl](http://www.trimbos.nl)).

#### *10. Encouraging participation in medical research*

In the late nineteen eighties Dutch government saw a role for patient organizations in the area of medical research. It was felt that policy issues regarding scientific research should not be decided by the government alone. Societal organizations ought to be involved, including patient/consumer groups. This would provide large societal support and a broad base for implementation of the results of scientific research (TK 20423 nr.2 p.53). A patient representative of the patient movement was awarded a seat on the Council of Health research, which has an important task in advising government on research priorities.

Some years after this statement was issued patient representatives were asked to comment on research proposals with ZonMw, the organization responsible for dividing the research budget in the health care sector (Klop et al. 2004, Smit et al. 2006). Other initiatives for patient participation in medical research were taken as well (Caron-Flinterman 2005, Smit et al. 2006).

#### **4. Assessment**

It is not easy to evaluate what happened to the patient movement in the Netherlands. On the one hand it seems clear that the government has utterly manipulated patient organizations. They have been organized, reorganized, merged and steered in all sorts of ways. The government has tried to use the patient movement as a stick to hurt the medical profession (remember the emphasis on the critical potential, that was deemed all important), the government has also used them to mobilize support for a major change of the insurance system (remember how the movement was urged to present a united front with regard to the insurance issue).

The government has lavished ever more tasks on patient organizations. It has asked them to participate in guideline groups alongside medical professionals. It has asked them to participate in medical research. Patient organizations have been invited to ever more advisory councils, consulting committees and other thinktanks or decision making bodies (Cf.

Rijkschroeff 1989). It seems extremely difficult to turn down such invitations. When you are a busy individual, being just that: an individual, you can say no when you are asked to participate in decision-making or advisory bodies. You can indicate that you are not that interested in the topic that the decision-making will be about. You can apologize and say that you are extremely busy or you can simply dismiss the invitation without any reason whatsoever. But when you are a patient organization, representing the interests of your members, it is not that easy to decline invitations, because the patients you represent might suffer because of your decision. You cannot plead a lack of interest, because obviously, you should be interested in everything that concerns your members. You can only refer to a lack of time and that is something that the government is willing to grant you. You can get extra time for free, because you are entitled to subsidy. If you follow the correct procedures you can get a lot of extra money and employ personnel. You can send paid staff to the meetings that you have been invited to attend. As a patient organization you seem to be confronted with an offer you cannot refuse. However, once your organization has come to depend on government money, it seems not altogether unreasonable that you should think *with* the government, rather than against it. It would hardly seem fair for the government to have to pay for people to oppose their plans, wouldn't it?

Should you consider opposing governmental policy, the government can, ever so subtly, point out that you have never been democratically elected by anyone. They can ask you to show whom exactly you represent and question whether your position is shared by your own members, or by patients in general. Of course, all these questions could be put to you at any time, they are just as important when you agree with the government, but somehow under those circumstances the questions simply do not pop up that often. They seem less important somehow. And of course, the government might decide to withdraw or reduce subsidy at any time for any pretext.

Patient organizations are very much aware of this dilemma. Should they opt for a position in the shadow of the government, with a lot of work and a bit of influence, and accept the fact that this will make them highly dependent on subsidy money? Or should they remain independent and forego the chance of influencing policy? Some organizations think that they can have it both ways: they ask umbrella organizations to think along with dominant political ideology, while the disease specific member organizations can cling to their independence. But most organizations choose the policy route, despite all the strings attached to it (Nederland & Duyvendak 2004).

Is it fair for a democratic government to put organizations in civil society in such an extremely dependent, vulnerable position? It can be done, and it seems to work, but is it fair? Or is this far too Machiavellistic for politicians in the 21<sup>st</sup> century?

On the other hand the bridging elements in patient organizations seem to have arisen precisely because of the governmental interventions questioned above. Patient organizations convene and merge with other patient organizations in coalitions or umbrella organizations because the government has encouraged them to do so, thereby enlarging the social networks of people who are active member of one disease specific patient organisation.

Patients meet with medical researchers and medical doctors because government has urged researchers and professional organizations to invite patient representatives in their midst. One may question whether democratization of medical research or democratization of the guideline development process can be sensible goals in the first place. In the case of medical professional guidelines one might say (and in fact the government and the medical profession have argued) that these should be “evidence based.” That is: they should be based on the results of scientific research, randomized clinical trials, not on anecdotal evidence or mere consensus. If that is the case, it is highly doubtful whether patient representatives can contribute anything substantial, since their input is often based on “experiential knowledge”, anecdotal knowledge of themselves or people like them (Van de Bovenkamp and Trappenburg, manuscript). In the case of medical research one may wonder whether patients really contribute ideas that researchers had not thought of themselves; in fact research has shown that having patient participate in research does not make much difference at all (Caron Flinterman 2005). However, from a social capital perspective, these are activities that bring patient representatives in contact with different people and different points of view.

Likewise, giving patient organizations a role in negotiations with health insurers, even asking them to strike deals for the sake of their members, may boost patients’ confidence in their own democratic skills: here they are, bargaining with the high and mighty.

Making a final judgment is difficult. Perhaps a government who would want to strengthen civil society should do so without making organizations utterly dependent on the government and thus vulnerable at the same time. That is: granting subsidy could be a good decision, but only if the subsidy would come with no strings attached and for a longer period, not if organizations have to go through a time consuming application procedure with lots of ifs and buts, resulting in a fixed amount of money that has to be answered for after a limited period in time. That would give organizations some room to manoeuvre. Even a



democratically chosen, benevolent government should tame the Machiavelli in its breast. Good ends do not justify arbitrary arrests, torture or the curtailment of constitutional rights. Nor should they justify making organizations enticing offers, which will make them utterly dependent and vulnerable but which they cannot easily refuse.

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## Interviews

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- Interview, 12-1-2006, ms. Paternotte, Balans
- Interview 25-1-2006 mr. Klumpen, Clientenbond
- Interview 27-1-2006 ms. Berman-Klein Obbink, mr. Mandema, Parkinson Patiëntenvereniging
- Interview 7-2-2006, ms. de Ronde, ms. Verschuur, BorstkankerVereniging Nederland

- Interview 20-2-2006, mr. Hof, Alvleeskierverseniging
- Interview 28-2-2006 ms. Beacher, Oscar sikkelcelvereniging
- Interview 9-3-2006 mr. Hummelen, mr. Treur, Friedrich Wegener Stichting