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## **The impact of patient advocacy. The case of innovative breast cancer drug reimbursement**

### ***Abstract (176 words)***

Current research into patient advocacy focuses on attempts of patient groups to mobilise resources and to influence researchers, pharmaceutical companies and policy makers. This paper adopts a 'framing political opportunities' approach to draw attention to other kinds of advocacy strategies. In a case study of breast cancer patient advocacy of Herceptin reimbursement it is shown how patient groups tried to gain access to policy making by means of three different opportunity-framing strategies. Articulation aims at creating awareness through public-agenda building. Negotiation aims at frame alignment between interdependent stakeholders by arranging meetings. Politicisation is a strategy to influence the agendas of political arenas. Patient organisations succeeded in creating awareness and support, which had a considerable impact on other stakeholders. These impacts in turn aided the politicisation of the issue. However, the final impact on reimbursement procedures was only partially achieved due to depoliticising counterstrategies based on persistent ideas buttressing a particular division of responsibilities in the organisation of health care. According to these ideas cost control in health care is a medical responsibility, not a political one.

Keywords: patient organisations, social movements, impact, health policy

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## ***Introduction***

Patient organisations are increasingly recognised as important stakeholders in decisions about research, development, prescription and reimbursement of new therapies. In his pioneering work Epstein (1995, 1997) showed how representatives of AIDS patients in the US actively contributed to the shaping of clinical research practices and HIV/AIDS therapies. Many studies have been conducted since then. Blume (1997), for example, analysed how the medical rhetoric of cochlear implants as artificial ears for deaf people provoked the counter-rhetoric of implants threatening the self-identity, community and sign language of deaf people. Rabeharisoa (2003) studied how funding scientific and clinical research granted the French Muscular Dystrophy Organisation a partnership role in decisions about the direction of future research. Regarding the Dutch context, Caron-Flinterman et al. (2005) addressed the contribution of patients' experiential knowledge to the agenda setting of biomedical research. Boon et al. (2008) analysed the representation of patient demands in the case of orphan drugs. In addition, attempts have also been made to bring the research results together. Academic journals have devoted special issues to the role of patient groups in biomedical decision making (Bonnet et al. 1998, Brown and Zavestoski 2004, Hess 2004, Landzelius and Dumit 2006) and an excellent review of the literature has recently been published (Epstein 2008). In this review, Epstein summarises how the work of patient groups challenges traditional conceptions of expertise and how scientific results, technological developments and state policies are often the upshot of heterogeneous practices in which patient groups play an increasingly important role.

In spite of this academic recognition of and focus on successful patient advocacy, patient organisations are in general only marginally involved in policy making. This article reports on research into the limited success of advocacy of breast cancer patients pertaining to the prescription and reimbursement of Herceptin, an expensive drug that is administered in hospitals.

In the mid-1990s, the Dutch Health Minister and Parliament debated the reimbursement of these drugs in the context of biomedical developments, growing health care costs and existing financing procedures. Each hospitalised patient enjoys a right to medically necessary treatment, including the administration of the appropriate registered drugs. Because hospitals have assigned budgets and can allocate them to different forms of treatment and care at their own discretion, the prescription of expensive drugs, of which Herceptin is an example, has implications for many other decisions. The viability of this reimbursement system was the issue of the parliamentary debates. The result of these debates was a temporal rule stating that *up to 75%* of the expenses for drugs on an ‘expensive medicines list’ should be financed by health insurance companies, the exact percentage to be negotiated between hospitals and insurance companies. The remainder should be paid from hospital budgets.

This outcome was sustained by a particular policy monopoly (Baumgartner and Jones 1993) that included policy actors, hospitals and reimbursement companies, but excluded medical specialists and patients. The responsibility for cost reduction rested on the shoulders of competing insurance companies, which would have to make agreements with care providers attractive to their customers, and hospitals, which felt a disincentive to administer expensive drugs if alternatives were available. Patient groups had no voice in the decision making about reimbursement criteria.

Herceptin was developed by Genentech and Roche and approved for marketing by the European Medicines Agency for metastasised breast cancer in 2000 and, after additional studies, also for early stage (adjuvant) breast cancer in 2006. Patient organisations were concerned about the ‘negotiable percentage rule’ and claimed that this was bound to lead to differences in administration of Herceptin between hospitals, regions and countries. They actively opposed the rule, as well as the underlying ideas about how costs should be controlled in health care. Organisations of patients aligned with organisations of specialists and engaged in strategies to combat the problem of unequal access in particular and the policy monopoly in general. But final impact on reimbursement procedures was only very partially achieved due to

counterstrategies based on the persistent policy monopoly sustaining the prevailing system of cost control in health care.

To gain insight into factors explaining (the lack of) patient advocacy impact, we develop a framework that builds on social movement theory and suggests how patient groups employ strategies to mobilise support in a variety of arenas. We follow patient groups and analyse their activities in these arenas. Apart from merely describing debates in which patient advocates attempt to reframe dominant ideas and policies, we also aim at discerning patterns of patient advocacy. These patterns might help patient groups in organising and choosing their strategies in future debates.

### ***Resource mobilisation, framing and political opportunity structures***

Patient advocacy pertaining to Herceptin reimbursement is an example of what in sociological literature is described as social movements. This literature consists of three major traditions that offer explanations for the emergence, dynamics and impact of social movements (McAdam et al. 1996b, Hess et al. 2008). Resource mobilisation theory focuses on organisational structures through which movements can mobilise people and other resources to engage in collective action. Frame analysis focuses on collective processes of interpretation, attribution and social construction, through which people share problem perceptions (diagnostic frames), prospects (prognostic framing) and action orientation (motivational frames) (Benford and Snow 2000). Political opportunity theory draws attention, usually in a comparative way, to changes in institutional structures that allow movements to develop and grow.

Most research on patient organisations, insofar it is concerned with advocacy strategies, departs from resource mobilisation theory. Successful advocacy efforts are explained in terms of the ability of patient organisations to mobilise resources in order to position themselves as ‘obligatory passage points’ (Callon 1986) for researchers, pharmaceutical companies and policy makers (Epstein 2008). Examples of such resources are experiential knowledge (Caron-Flinterman et al. 2005), crucial information about family inheritance (Nukaga 2002), efficiency

analyses, surveys (Murphy 2004), funding to conduct research, or patients to enrol in clinical trials (Epstein 2008). By the same token, patient groups with less access to strategically important resources will find it more difficult to assert influence. They may want to bring in perspectives or experiences that are not immediately perceived as relevant by other stakeholders. They may have severe difficulty in persuading audiences of the importance and urgency of their demands and concerns. Their limited influence could be explained by their lack of strategically relevant resources and failure to position themselves as obligatory points of passage.

We do not find this a satisfying explanation. There may be more reasons for failure, such as a patient group's inability or unwillingness to articulate its demands and concerns to the right audiences, its failure to align these concerns with the interests of other stakeholders or the strategies of others to downplay the demands of patients. This article explores the variety of reasons why strategies of patient advocacy succeed or fail.

We draw on a fourth approach in social movement theory, which attempts to build bridges between theories of resource mobilisation, framing and political opportunity structures (McAdam et al. 1996a). In this synthetic framework Gamson and Meyer (1996) introduced the concept of 'framing political opportunities' to emphasise that opportunities are not passive and given, but actively constructed in the process of seizing them. Especially opportunities pertaining to relatively volatile elements of political structures are seized by social movements to influence other agendas. In the next section we discuss three complementary strategies with which they might do so.

Moreover, the patient organisation in our case employed these strategies to challenge a more stable political structure. The object of reframing was a robust idea buttressing the policy monopoly to which they had limited access, namely the idea that cost control should be fostered with market mechanisms. The notion of 'buttressing ideas' serves to explain why policy monopolies typically remain dominant for decades (Baumgartner and Jones 1993, Baumgartner and Jones 2002). Policy monopolies are institutional arrangements that reinforce dominant

political understandings concerning the policy of interest. These arrangements are buttressed by ideas that are generally connected to core political values that can be communicated directly and simply through image and rhetoric. Examples of such ideas are progress, independence from foreign domination, fairness and economic growth. In our case the neo-liberal idea of cost control co-ordinated via the health care market is the dominant idea that patient organisations challenged. This idea buttressed the participatory arrangement that excluded medical professionals and patient groups and that made it difficult for them to express their views and influence policy.

Reframing buttressing ideas is a strategy of patient groups to foster participation in policy monopolies. In their work on patient organisations in the context of the UK National Health Service, Baggott et al. (2004) suggest how this might work: ‘Such monopolies may be challenged by previously excluded groups, who set new agendas and redefine problems. These challenging groups *choose arenas* where their resources, skills and expertise have greatest value. If successful, institutional changes lead to the incorporation of groups and their values within a new policy monopoly’ (p. 14, emphasis added). Patient organisations seek entrance to different kinds of arenas, the agendas of which they try to influence: media arenas, public arenas, electoral arenas and governmental arenas (McCarthy et al. 1996). Via these agendas they try to recruit bystanders among different audiences by creating frame resonance.

Frame resonance depends on two factors: the qualities of the frame and the strategies and tactics of the actors. While the necessary qualities of the frame have been dealt with in the social movement literature on collective action frames (Benford and Snow 2000), we focus on actor strategies. How do patient organisations challenge buttressing ideas by influencing agendas and persuading audiences in different arenas? How do they choose arenas to try to (re)shape agendas? Realising that arenas are not independent spaces, but linked in such a way that audiences in one arena may be gatekeepers of other arenas, the question becomes how patient groups employ strategies to shape these linkages. We refer to this process as framing political opportunities more towards the volatile end (in contrast to stable buttressing ideas) of

the institutional spectrum (Gamson and Meyer 1996). In the next section we propose a distinction between three complementary strategies: articulation, negotiation and politicisation. This distinction serves to show how patient advocacy efforts may be patterned by particular sequences of strategies. Simultaneously, it offers a new perspective on how to conceptualise and study patient advocacy impact.

### ***Three strategies of opportunity framing***

Instead of departing from a distinction between pre-given institutional arenas, we propose a distinction between complementary strategies to frame political opportunities. Schattschneider distinguishes two basic types of strategies that actors involved in a political struggle might employ: proliferation and containment. With proliferation social groups, usually weaker ones, try to widen a conflict by engaging a broader audience and recruiting new allies to an issue. Containment means that social groups, often dominant ones, aim at settling the issue by disengaging or assimilating critical audiences (Schattschneider 1960, Marres 2005). In this article we suggest refining this typology. We define three complementary strategies, each of which could result in proliferation or containment.

*Articulation* is a strategy with which patient groups choose and shape arenas that enable them to express their action frames and underlying views and values. Public protest, open letters and demonstrations are typical examples. Articulation is most often organised to obtain media coverage. The targeted audience consists of possible supporters, with whom patient groups want to form an alliance in their opposition against a particular policy monopoly or buttressing idea. As Kolker (2004) shows, an effective strategy to attract media attention to an issue is to draw on existing cultural frames and symbols prevailing in the audience. Articulation proliferates when it creates awareness of and sympathy for the patient group's action frame. If patient groups fail to persuade bystanders, we speak of de-articulation. Established ideas then contain the voice of patient groups.

*Negotiation* is a strategy with which interdependent stakeholders attempt to form alliances. Alliances are a crucial resource for patient advocacy groups (Baggott et al. 2004) and come about by organising bilateral meetings, brainstorming sessions or consultations. To some degree stakeholders may already have aligned frames partly because of previous articulations. Negotiation is not directly targeted at a particular audience, because the involved stakeholders are primarily oriented at persuading each other. A common enemy may, however, be an important motivation for stakeholders to engage in negotiations. Negotiation requires important political skills and the capacity to align one's frame with other more or less complementary frames. The impact thus depends on finding and emphasising common elements in different frames. Here, containment acquires a positive meaning denoting the creation of consensus on a particular framing of ideas. While negotiation is often crucial for patient groups to achieve an impact, it clearly does not provide a guarantee. Other stakeholders may resist compromising their frame and prefer to go their own way leading to further, but unproductive, proliferation.

*Politicisation* is a strategy to influence the agendas of political arenas. Participants in these arenas are authorised to make decisions based on their representative legitimacy. Typical examples of arenas are city councils and parliaments, within which power disparities are assumed to reflect the will of the electorate. The electorate is the audience, whose expectations are anticipated in order to show that it is being represented. When patient groups engage in articulation and negotiation processes, they seek to influence those who are influential in political arenas: politicians, the electorate audience or social groups in other arenas who have a similar interest in persuading politicians and their audience. If successful, politicisation leads to proliferating debates about buttressing ideas and the specific problems they create. If not successful, we speak of depoliticisation. Depoliticisation leads to containment and occurs when majorities are not willing to question policy monopolies and buttressing ideas, because they do not share the values underlying the patient group's action frame.



## ***The case of Herceptin reimbursement***

A case study is conducted to reveal examples of these different strategies and show how they contributed to the impact of a patient group on policy making. We aimed at revealing patterns in patient involvement and impact by exploring how articulation, negotiation and politicisation followed each other and built on each other's outcomes.

The data used for this case study are obtained from the archives and public websites of the Dutch Breast Cancer Association (BVN) and other actors involved. These other organisations included medical specialist groups, Parliament, the health ministry, other patient organisations (such as the Dutch Federation of Cancer Patient Organisations (NFK)), representative organisations of the pharmaceutical industry, insurance companies and hospitals. The sources (598 in total) included archival records, policy documents, letters, parliamentary proceedings, annual reports, evaluation reports and minutes of board and committee meetings of these organisations. These were complemented with articles from Dutch newspapers. The open access material was searched using keywords (such as Herceptin, reimbursement, etc.). For most of the organisations the sources were used that were made available to us, whereas in the cases of BVN and NFK the complete archives were searched. By means of a snowball method (Bijker 1995) references to meetings, policy documents, project proposals and other sources of information were found. In addition, we conducted fifteen interviews with representatives of these organisations ranging from chairmen and managing directors to researchers and secretaries. The aim of these interviews was to clarify interpretations of the written material, in this way creating a more validated and informed story. The written and interview material yielded 2503 events and statements from which we were able to draft our case study. These stories were checked by three key informants in the Dutch health care field.

The overall story can be divided in two episodes. In the first patient organisations convinced the minister of health to change the reimbursement rule; he did so while keeping underlying ideas mainly intact. In the second episode, the patient organisations continued to

oppose these ideas as the main source of the still existing problem of unequal access to expensive medicines.

### ***Episode one: solving the problem without structural change***

Between 2003 and 2005 the BVN and NFK actively drew attention to the problem of unequal access to expensive medicines like Herceptin. The final impacts of their strategies were not realised until the issue passed a sequence of arenas with different agendas. These framing strategies can be divided in articulation, negotiation and politicisation. Figure 1 depicts the relations between these strategies as they occurred in the first episode.

**<< About here: Figure 1. Patterns of strategic efforts in the first episode (2003-2005)>>**

#### **Articulation**

In open letters to the Dutch Parliament two organisations of oncologists warned that the situation of the then existing reimbursement regulation would lead to serious problems of unequal access. Hospital budgets were stretched to the limit by expensive medicines and medical specialists had to make decisions based on financial arguments instead of what is called ‘standard medical treatment’. This would not only lead to underdiagnosis, undertreatment and differences between regions and countries, but also to a violation of medical professional autonomy. In association with the BVN and NFK they questioned the dominant idea that a negotiable reimbursement percentage is a good mechanism for cost control in health care by pointing to undesirable consequences of this mechanism. Their articulation strategies took the form of sending letters, organising meetings and attracting media attention. Newspapers devoted ample attention to the debate and an influential current affairs television programme broadcast an item on this issue featuring two medical specialists. In these media, the term ‘postcode care’ was used to denote the unequal access to drugs. The Dutch hospital representatives added

figures indicating that in about one-third of the hospitals less than 75% of the total drug costs were reimbursed by insurance companies.

The oncologists' organisations furthermore produced a report indicating that 20% of the hospitals had problems and released a letter in which they calculated the costs for the health care system if hospital departments would work with 100% reimbursement. These indicative figures showed that there was no strong need to maintain the current reimbursement rule. The two organisations sent another letter, together with the NFK, to Parliament urging the minister to take action.

In a consultation round, the minister (who was not convinced that inequalities actually existed) asked the stakeholders for concrete information about patients who were not treated, the kind of considerations, the hospitals involved and the kind of communication between physicians and insurance companies, hospital boards and patients. Insurance companies claimed that hospitals should use their own budgets to avoid undertreatment, but organisations representing hospitals and pharmacists argued that drugs should be 100% reimbursed if they were decreed part of standard medical practice by medical professional groups. Patient groups continued stressing the unacceptability of 'postcode care' and said that patients were ill-informed about whether they were treated with the right drug, and were unable to communicate with physicians and insurance companies about this issue. They also questioned the dominant idea of cost control via financial incentives to hospitals. They thought that health care costs could be better balanced by means of a (political) discussion about the maximum price for every year of life gained.

Meanwhile, the BVN had taken another initiative to counteract the minister's response that the unequal access problem was merely hypothetical. It published a report with more concrete figures revealing undertreatment and differences between regions and countries in Herceptin usage. The accompanying press release featured a breast cancer patient having had great difficulty in gaining access to Herceptin.

In articulating the urgent problem of unequal access to expensive drugs, patient organisations, among others, preferred a strategy of writing open letters to convince a wider audience of their problem interpretation. This appeared to be particularly effective when they led to media coverage. The use of ‘postcode care’ as a rhetoric device can be seen as an example of framing opportunity. These two words summarise a complex problem and at the same time augment the unfair aspect of it. The case of an individual patient used in a press release is another example. In terms of (intermediate) impact, problem awareness was achieved by employing such framing strategies.

A constraining characteristic of this framing, however, was that the dominant idea buttressing the policy monopoly that maintained the current reimbursement rule was hardly questioned and remained unaltered. Media are more interested in problematic cases and controversial quotes. Questioning the dominant idea would require a more ideological discussion with the minister of health (i.e. politicisation).

### Negotiations

Negotiations are aimed at the sharing of frames by interdependent social groups. Although frame sharing can be a result of independent but similar articulation processes, it is often an intentional result of deliberate meetings. The open letter sent by organisations of oncologists was preceded by negotiations with BVN. They appeared to share problem interpretations. The joint letter urging the minister to take action was also preceded by negotiations. The BVN and the oncologists’ organisations, together with the NFK and the patient organisation on Hodgkin’s lymphoma, gathered together and negotiated how they could act collectively towards the minister. Negotiations thus contributed to collective articulation.

The consultation by a representative organisation of its constituency is a somewhat different example of negotiation between interdependent groups. This, for example, happened when the organisation representing Dutch hospitals conducted a survey of its members. Again, this survey preceded the articulation of their interpretation.

Negotiations are often devised to support the politicisation of issues. Parallel to the production of the BVN report on Herceptin, patient groups again engaged in a discussion with medical specialists, but this time also with hospital representatives and, crucially, a number of parliamentarians. The patient groups stated that the government did not guarantee accessibility, safety and quality of health care with the current regulation. Meanwhile, medical specialists argued that the profession's autonomy was under pressure, because physicians were put in a 'devilish dilemma', having to answer to both their patients and their hospital boards. These kinds of arguments would also feature in the subsequent parliamentary debate.

Negotiation is a strategy for social groups to compare their views and perspectives with those of others and to recruit supporters or collaborators for their action frames. Negotiation first contributed to linking patient organisations with organisations of medical specialists to articulate concerns together. Later, these groups succeeded in aligning hospital representatives and parliamentarians. As complementary strategies, articulation and negotiation both aided the politicisation of dominant ideas.

### Politicisation

The issue was discussed in Parliament a couple of times. The first time, just after the broadcast of an influential current affairs television programme, the Health Minister was obliged to react. He said that hospitals should use their budgets for the administration of expensive drugs if necessary. He also sent a letter to Parliament in which he stated that the information provided by the advocating stakeholders lacked precision on concrete situations and figures of drugs that were not prescribed, on the position of hospital boards and on agreements between hospitals and insurance companies. Thus, in response to politicisation, he tried to depoliticise the problem. To the minister the mere suggestion that the reimbursement situation *could* lead to unequal access was not sufficiently convincing. He did not intend to change the reimbursement procedures.

Pressure continued to be exerted in Parliament. At the end of 2004, Parliament was to meet over health issues and many stakeholders, including representatives of medical specialists,

patients and hospitals, had sent letters to articulate their views. Parliamentarians explicitly referred to the letters about the problems with expensive intramural drugs. The issues put forward were similar to those articulated by organisations of patients and medical specialists. The Health Minister reacted that he was in favour of transparency, equality and autonomy, but at the same time he was still not convinced about the scope of the problem. Further investigation and consultation would be necessary. Nevertheless, a motion was accepted stating that the minister should devise a new reimbursement rule that would better guarantee equal access to expensive medicines and would relieve the dependency of physicians on the negotiation skills of their hospital boards.

The minister's subsequent proposal offered a partial solution. Hospitals, medical specialists, pharmacists, patient groups and a number of parliamentarians had jointly articulated their desire for 100% reimbursement by insurance companies. The BVN report, with more concrete figures, had received much media coverage and led to two series of questions by parliamentarians to the minister. There was clear dissatisfaction among stakeholders as well as within Parliament. Only insurance companies thought that hospitals should also partially contribute. In spite of this dissatisfaction, the minister claimed that hospitals, physicians and the Health Inspection had not reported complaints about undertreatment during the consultation. For this reason the new proposal only comprised a fixed reimbursement percentage of 80% for every hospital. The minister did not increase it to 100%, because he wanted hospitals to strive for cost-effectiveness themselves. He thus offered a solution to the problem that many stakeholders had with the dominant idea of market-driven cost control, yet without dropping this idea itself.

Because parliamentarians are a vehicle for politicisation, they have been an important audience for articulation and an attractive negotiation ally in the struggle for reimbursement. Politicisation thus served to put the fear of health inequalities at the centre of the parliamentary debate. The minister was increasingly forced to change the reimbursement rule, but he managed to safeguard the dominant idea buttressing the established arrangement of responsibilities.

### Episode one: results

In this first episode, the patient associations achieved an impact by means of correspondence with medical specialists, sending letters to Parliament, the production of a report on Herceptin undertreatment, striving for media coverage and the persuasion of parliamentarians. Coalitions were built when stakeholders actively negotiated a collective politicisation strategy, but also when various social groups articulated similar views. By these means, hospital representatives and parliamentarians joined forces. While the minister initially tried to depoliticise the issue by stating that the problem was very hypothetical, he could not maintain this position when facing an increasingly broad coalition of opponents. He finally came up with a solution with which hospitals would still feel an incentive to strive for cost-effectiveness. Since this was the buttressing idea, he solved the problem without affecting existing policy monopolies. Precisely for this reason, however, the issue was not settled definitively. The second episode discusses how patient groups continued their battle in the years to come.

### ***Episode two: losing the battle?***

The second episode took place between 2006 and 2009. Patient organisations continued to strive for 100% reimbursement for expensive drugs in general and Herceptin in particular. We discuss the different opportunity framing strategies again under the headings of articulation, negotiation and politicisation (Figure 2).

<<About here: **Figure 2. Patterns of strategic efforts in the second episode (2006-2008)**>>

### Articulation

The patient organisations were ambivalent about the new reimbursement rule. On the one hand, the rule confirmed that the prescription of expensive drugs on the list would be met with financing, and thus in principle saved the autonomy of physicians and the right of patients to

receive adequate treatment. On the other hand, whether this actually happened still depended on decisions by physicians and hospitals, who continued to have an incentive to be economical in administering expensive drugs. In letters to the health ministry, the BVN warned that it might move towards the legal system or the media in the case that access to Herceptin was again denied to eligible patients.

Meanwhile, the Health Inspection investigated claims of Herceptin undertreatment. On request, the BVN sent a letter containing fourteen anonymous examples of women who had not received proper Herceptin treatment. However, in order to proceed with an official complaint, the inspection needed personal details of these women. Because the BVN – and other actors like doctors – could not provide this privacy-sensitive information, the Health Inspection was not able to report evidence for the claims to the minister, resulting in de-articulation of the issue. The Health Inspection recommended patients to make formal complaints individually.

Because convincing the minister proved to be extremely difficult, different patient organisations had started working jointly on drafting advocacy reports. In February 2007, the BVN and the patient group on Kahler's disease (Contactgroep Kahler) released reports on the prescription and usage of Herceptin and Velcade, respectively. According to these, undertreatment and differences between provinces and countries still prevailed. The patient organisations again claimed that expensive drugs should be 100% reimbursed and that cost control in health care should be arranged differently. They had repeatedly suggested that a political debate could be initiated about the maximum costs per treatment per year, e.g. based on the ultimate price of a saved year of life that society is willing to pay. This had not been common practice in the Dutch context so far.

The reports were immediately followed by a 'patient manifesto', published by the NFK in association with different groups of patients, physicians and pharmacists. The manifesto targeted the Dutch Parliament and claimed that unequal access to innovative drugs was a continuing threat despite new regulations. In an accompanying document, the mutual dependencies between stakeholders (i.e. medical specialists and hospital boards) were analysed,



which explained why they were not eager to come forward with concrete figures and cases of undertreatment. The manifesto also reported that the problem of undertreatment was wider than hitherto recognised. Especially drugs beneficial for children with cancer and patients with a rare type of cancer, or with complications, were not reimbursed, because these prescriptions did not comply with the requirements of the expensive drugs list. Another problem was that some diseases were treated in only a few specialised medical centres, causing a heavier financial burden for these centres if expensive drugs were used for treatment. The manifesto concluded that the government should seek a more structural solution to these problems and should not transfer them to hospitals that constantly had to make trade-offs between financing expensive drugs and e.g. nurse wages.

Articulation continued in the same vein as in the first episode. Patient organisations looked for publicity to create awareness and move parliamentarians to action. In terms of the object of articulation, the case became more articulated in its context. One aspect of this context is the mutual dependencies of stakeholders, making it difficult to present the concrete figures that could convince the minister. Another aspect of context was that other patient organisations faced similar problems. Instead of being the main problem, Herceptin undertreatment increasingly became articulated as one of several cases of reimbursement problems with expensive drugs. Different patient organisations started negotiating common strategies to challenge the dominant idea of market-driven cost control in health care.

### Negotiations

More than before patient organisations aligned frames and collaborated to build a stronger case. A broad discussion group was formed by the NFK, including patient organisations working on breast cancer, rheumatism, Crohn's disease, Kahler's disease and asbestos cancer. In order to influence an after-one-year evaluation of the new reimbursement procedures and the upcoming elections, this group discussed possibilities to produce a new lobby document in the autumn of 2007. They decided that the collected data were not yet sufficient to substantiate a critical report

before the elections, but they might be for the evaluation in early 2008. By then, some of the patient organisations struggled to collect their data for several reasons. Only data on breast cancer and Kahler's disease were included in the published report and a press release. The co-publication of the two reports and the patient manifesto were important outcomes of these negotiation processes.

In addition, the reception of these reports showed that the coalition was even broader. The hospital representative organisation and the umbrella organisation of medical specialists' groups reacted in favour of the claims and viewpoints.

Negotiation is a strategy to foster frame alignment. Patient organisations realised that they could make a stronger case together. They not only encouraged each other to write case reports, but also made a collective effort by producing a patient manifesto based on several broad discussions in which organisations exchanged experiences and viewpoints. However, despite this collective effort and the support of other stakeholders, the patient organisations failed to foster the re-politicisation of an, in their eyes, 'untenable' situation.

### *Politicisation*

The patient organisations' case reports and manifesto were meant to influence the formal after-one-year evaluation of the new reimbursement rule. However, this evaluation was presented earlier and had a positive tone. The minister claimed to be satisfied especially because the Health Inspection had only received a few complaints about the reimbursement and prescription of expensive medicines, which all led to acceptable solutions. While the patient organisations were explaining why it was impossible to present the kind of evidence desired by the minister, the minister used the relative absence of such evidence as an argument for a positive evaluation. He again depoliticised the issue. This becomes even clearer when considering the responses to the evaluation in the wider societal arena. The hospital representative organisation rephrased the conclusion as an inappropriate 'good news' message. It sent a letter together with four organisations of medical specialists and three patient organisations (following negotiation).

Apart from articulating their interpretation, they claimed that they should have been involved in the evaluation. The patient manifesto presented two months later substantiated this claim on behalf of patient organisations.

The new Health Minister reacted to the manifesto by sending a letter to Parliament conveying almost the same message as his predecessor. He stated that the ministry could not find sufficient evidence of undertreatment. The minister specifically commented on the Herceptin and Velcade reports: they still did not make sufficiently clear what the reasons behind the presumed undertreatment were. It could have been tight hospital budgets but other reasons were equally possible. For these reasons, the minister only decided to commission an external investigation to map the considerations and reasons behind decisions made in hospitals about access to and treatment with expensive medicines. This investigation ran for more than a year until mid-2009. In the meantime the issue was pigeonholed and parliamentarians focused their attention on related matters, such as extramural reimbursement and the revision of the hospital financing system. In dealing with these other matters, it seems that not only has the problem of expensive drugs in hospitals become obsolete but also that strongly embedded ideas buttressing the policy monopoly also dominated the direction in which solutions for other policy issues were sought.

In arenas where such ideas could be politicised in principle, patient advocacy efforts might lead to impacts on public policy. One condition is that the action frame of patient organisations is aligned with frames of powerful groups within these political arenas. However, there was hardly any debate in Parliament following the evaluation and the patient manifesto. The positive evaluation as a first attempt to depoliticise the issue only raised a dispute in the wider societal arena. The second attempt seems to have settled the policy monopoly definitely. The investigation into hospital finances was exclusively focused on individual considerations and decisions of patients, physicians and boards in hospitals, not on health policy in a broader sense. These problems might indeed be solved without changing basic policies and core ideas. Moreover, because of the interrelatedness of financing problems, dominant ideas provided

orientations to solve other problems as well. Although the investigation is still under research it looks like the patient organisations have lost their battle.

### **Episode two: results**

In this second episode, the most important impacts resulted from the collaboration of several patient organisations. This enabled them to articulate undertreatment with expensive medicines as a problem in multiple disease areas and embedded in a problematic division of responsibilities. However, repeatedly articulated interpretations were depoliticised before leading to impact on policy. The dominant idea that health care cost control is the responsibility of insurers and hospitals contained such interpretations.

### **Conclusions**

In this paper we described advocacy efforts in the context of decision making on the reimbursement of expensive drugs in the Netherlands. These discussions ran over the course of several years and were subdivided by two episodes. They were characterised by a variety of arenas, agendas and strategies to frame these as political opportunities for patient advocacy. The concept of framing political opportunities highlights that opportunities are not just presented, but need to be constructed and actively given shape.

This paper aims to make two contributions to the literature. Firstly, advocacy discourses were analysed in a systematic and structured way in order to describe and explain policy-related debates and discussions pertaining to multiple stakeholders, frames and arenas. The case study of Herceptin reimbursement advocacy shows that the Dutch Breast Cancer Association (BVN) was successful in putting the *problem* of unequal prescription of Herceptin on the agenda in various arenas, but failed to convince the dominant actors that the source of the problem is the dominant idea that health care cost reduction is a medical responsibility instead of a political one. In the first episode the patient organisations successfully articulated and politicised the problem and putting it on the agenda of the politicians by joining forces with medical specialist

groups and other professional representative organisations. Moreover, they supported their advocacy efforts and coalition building by producing facts and figures of their own. Parliament and the Health Minister could not ignore these signals, although the Health Minister came up with a different solution than envisioned by other stakeholders. In the second episode the patient groups hardly influenced the problem definition and dominant ideas because, even though they negotiated common strategies in a broad coalition, the kinds of arguments that were articulated did not essentially differ from those articulated in the first episode and were partially assimilated by the new reimbursement rule. A complementary reason is that the 2007 elections were less a window of opportunity than was hoped for. These had not resulted in a radically new balance of power, which might have been more favourable for patients' kinds of arguments. On the contrary, other parliamentary debates, such as those leading to a new health insurance system and a new hospital funding scheme, rather proved to reinforce the existing policy monopoly and its buttressing ideas. Patient groups had little opportunity to link up with these debates.

Secondly, we aimed to reveal patterns in patient involvement and impact. The concept of opportunity framing strategies offers an informative perspective on the effectiveness of patient advocacy. Our analysis suggests that articulation and negotiation are stepping stones to the politicisation of issues. Because patient organisations often fight for specific and partial interests, they are hardly ever in a dominant position. Their advocacy efforts take place in different arenas with heterogeneous actors and interests. In this case, strategies employed by patient groups, such as shared agenda building and producing facts and figures, had a considerable impact on other stakeholders. These impacts of articulation and negotiation in turn aided the politicisation of the issue. However, the final impact on reimbursement procedures was only partially achieved in the first episode and not at all in the second due to depoliticising strategies based on the persistent dominance of a market agenda for cost control in health care.

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