



Stronger, but not (yet) an equal. The use of quality improvement instruments and strategies by patient organisations in the Netherlands



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ABSTRACT

This article deals with the questions *what the benefits and limitations are of the instruments and strategies that patient organisations use to influence quality of care*. The advocacy of patients' interests has become more important for patient organisations in recent years, which is partly due to Dutch health care policy reform. Thirty state funded quality improvement projects run by patient organisations between 2009 and 2012 have been analysed. The quality improvement instruments developed and used in these projects are concerned with: standardization and standard setting (*What is good care?*); consultation, comparison and checking (*What is the state of the care given?*); and negotiating and advising (*How can quality of care be improved?*). The choice for these instruments is partly based on patient organisations' strategies of *scientization*, *valuing institutionalized methods* and *valuing good relationships*. We see that the development and use of these quality improvement instruments do strengthen patient organisation and therefore have internal identity and organisational effects. However, the external effects patient organisations can have by using these instruments and strategies is limited or at least insecure by lack of economic capital after the development phase and lack of negotiating power. The external effects of these instruments and strategies depend largely on a patient organisation's network and the willingness, degree of openness and policy of other stakeholders to cooperate. Therefore, these forms of patient participation remain vulnerable.

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1. Introduction

This article is concerned with empowerment of patients at the macro level, meaning the collective voice of patient organisations. The main activities of Dutch patient organisations have traditionally been to offer support, give information and to look after patients' interests. In recent years the latter activity seems to have become more important. One way of looking after patients' interest at a collective level, is to influence quality of care. Many projects to influence quality of care from patients' perspective have been set up. Patient organisations have participated in these projects. It is not yet clear, however, to what degree this participation has been successful, which leads to the following research question. *What are*

the benefits and limitations of the instruments and strategies that patient organisations use to influence quality of care?

2. Theory

One could state that 'the patient movement' in the Netherlands cannot be characterised as such because it contains a large variety of types of organisations for many different diseases, syndromes and conditions (Berk et al., 2008; Nederland et al., 2003; Schipaanboord et al., 2011). Traditionally, especially from the nineteen seventies and eighties onwards, collectivisation of patients and proxy took place with regard to mental illness, disabilities and chronic illness. In addition to these, more universal network and umbrella patient organisations have been founded.

By the beginning of the twenty-first century hundreds of patient organisations were active that differed in size, in financial means, in contacts, in the groups they represent and in the degree to which

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they are professionalized (Berk et al., 2008; Kamphuis et al., 2012; Nederland and Duyvendak, 2004). Their activities may be directed at strengthening their own organisation and members (*internal effects*) or at other stakeholders (*external effects*). *Internal effects* relate to both identity and organisation effects. A patient organisation tries to achieve identity effects when the sense of identity of a group or individual patients is reinforced, for example by organising support group meetings. Organisation effects are what a patient organisation is trying to achieve by improving the organisational structure of an organisation, by employing a professional administrator for example. *External effects* can be subdivided into the following four effects: 1) actions have a *sensitizing effect* when the patient organisation makes other parties aware of its demands or when these demands are put on the agenda; 2) actions have a *procedural effect* when a patient organisation manages to gain access to the decision-making process or when the organisation is (formally) recognized as a discussion partner; 3) actions have a *substantial effect* when the demands of a patient organisation are actually met, thus when patient representatives actually influence the decision-making process.; and 4) actions have a *structural effect*, when the socio-political opportunity structure for patient organisations changes (Nederland et al., 2003).

Among other ways, patient organisations have tried to look after patients' interests by participation in the improvement of quality of care. In patient participation literature two types of reasons have been put forward as to why patient participation is considered valuable. The first values patient participation as a *purpose in itself*, such as the democratic right patients have to influence what they are affected by or the improvement of accountability within health care policy. Secondly, more instrumental reasons have been put forward that value participation as a *means*, such as making use of the unique knowledge patients contribute in the form of experiential knowledge or improvement of the social basis for the implementation of new policies (Boivin et al., 2009; Bovenkamp et al., 2010; Callahan, 2007; Teunissen and Abma, 2010).

Reforms in Dutch health care policy have put more emphasis on the empowerment of patients. This is the result of the introduction of regulated competition in this field in 2006 (Health Insurance Act; Healthcare Market Regulation Act). To a certain extent the government has withdrawn and left more of the regulating and coordinating of the health care system to a 'power triangle' of insurers, providers and health care users in a regulated market system (Bouman et al., 2008; Raad voor Volksgezondheid en Zorg, 2010; Schipaanboord et al., 2011). Health care providers and insurers are connected in the health care provider market. With the regulated competition introduced in 2006, health care providers are supposed to compete over price and quality (Bouman et al., 2008; Nederland et al., 2007; Schipaanboord et al., 2011). Health care users are expected to be able to influence insurers and providers as consumers who have a choice in the health insurance market and in the health care provider market (Victoor et al., 2012). Giving individual patients more choice is however not assumed to suffice to empower patients. In order to enable health care users to function as well-informed, critical consumers, the focus lies on transparency. Transparency of price, quality and other health care characteristics is considered important (Bal, 2008; Zuidgeest, 2011). In addition to this, patient influence is only expected to function when individual empowerment is accompanied by empowerment at a meso level (e.g. client councils) and at the macro level of patient organisations. For example, patient organisations can try to influence the quality criteria that insurers use to value the care offered by providers. In line with this policy, Dutch government has offered these organisations funding (Ministerie VWS, 2008–2009). The governmental scheme offers structural financing and project grants in order to create and support organisations that can function as

'strong representatives'. An independent counsel grants the subsidies, while the office work is carried out by *Fund for Patients, Disabled and Elderly (PGO Fonds, from now on 'PDE Fund')*. Consequently patient organisations should be able to function as a *third party*, which means they can negotiate and cooperate as an *equal* with health insurers and providers (Arnstein, 1969; Teunissen and Abma, 2010). In line with these developments Dutch patient organisations have taken all kinds of initiatives to influence quality of care in recent years. A number of these initiatives were subject of the analysis presented in this paper.

3. Methods

In order to analyse *the benefits and limitations of the instruments and strategies that patient organisations use to influence quality of care*, it was decided to analyse ongoing projects. Therefore, a number of projects run by patient organisations that were granted government subsidy in 2009 have been selected.

The research is concerned with the benefits and limitations of the instruments and strategies that patient organisations have chosen to influence quality of care. Therefore, we selected patient participation projects with an *external instrumental goal, which are directed at stakeholders outside of the patient movement who can influence quality of care*. The external instrumental goal had to be concerned with quality of care. Applying this selection criterion was expected to lead to the inclusion of a broad spectrum of quality improvement instruments. Whether or not quality of care for the represented patients will actually be improved in practice due to the development and use of quality improvement methods, is a question that goes beyond the scope of this article.

First, a broad selection of 57 projects was made according to this selection criterion and on the basis of the concise public information about the projects. Then, the PDE Fund asked the patient organisations permission to give us as researchers access to the official project documents. A few organisations did not react to the request for permission. A more precise selection was then made by screening the project descriptions in the subsidy requests made by the patient organisations. This procedure has led to the inclusion of 30 projects, of which an overview is giving in [Appendix 1](#).

Five organisations run more than one project. The patient organisations that run the projects differ, in size, in financial means, in contacts, in the groups they represent and in the degree to which they are professionalized. All projects started in 2009 or 2010. While the majority of projects run until 2012, some had already been finished in 2010 or 2011. Other projects were extended beyond 2012. The data collection consisted of semi-structured interviews with 31 representatives of the patient organisations and an analysis of formal project documentation organisations were obliged to deliver (project plan, annual reports, and final report). One or more interviews were held, depending on the duration of the project. Some respondents represented more than one selected project and some projects were represented by more than one respondent. The respondents were the professionals or volunteers who were the main coordinators or organisers of the selected project. The following issues were addressed by the interviewer. How did the project develop up until the interview? What forms and levels of patient participation were adopted in the project, and how did this work out? Which quality improvement instruments were developed or implemented, and how did these work out? What other parties did you try to influence or try to cooperate with, and how did this work out? What does a patient organisation need in order to use the quality improvement instruments in question? How does the respondent expect the project to develop further? The semi-structured interviews with 31 respondents were recorded and fully transcribed. The interviews were done individually by

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