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Patients at the negotiating table: exploring appraisal criteria of health research and quality of care used by patient advocacy groups in The Netherlands

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Abstract

Background: Western Governments and the public at large acknowledge the importance of strong patient advocacy groups. A new type of involvement has emerged: patient representatives at the negotiating table, the patient group negotiating as a collective with other stakeholders. However, patient representatives feel inadequately equipped. This study was designed to identify 'issues that matter' to patient groups in The Netherlands and whether these issues are brought to the healthcare and research negotiating table between healthcare providers and health researchers.

Methods: Using a qualitative approach, the extent to which patients are involved in the assessment of health research and quality of Dutch healthcare from a patients' perspective was explored and also which criteria they use. A literature search, participant observation and interviews were carried out.

Results: The results demonstrate that patients are mainly consulted on an individual basis, but are to a much lesser extent involved as a group. There are patient criteria and guidelines in use for assessment of the quality of care, but there is virtually none for assessment of health policy and research. Many patient criteria are poorly operationalized, vague and abstract and are difficult to apply in practice.

Discussion and Conclusion: Based on these results the authors propose and discuss a new concept: a list of patient criteria for evaluating health research, policy and quality of care. These should be developed in dialogue with patient groups. A list of such criteria is expected to be of practical use to many patient advocates in many countries.

Keywords

Appraisal, commitment, decision-making, experiential knowledge, health policy, lay expertise, lung patient, medical research, participation, patient advocates, patient involvement, patient preference, person-centered care, quality of life

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Introduction

The recognition of the importance of the patient's voice being heard – and not only in the individual patient-doctor setting – is increasing. The political impact of patients as a collective is also equally important for health-related research, policy and quality in Government institutions and private organizations. Patient involvement in the decision-making process is currently a subject of great interest and is being advocated at many levels [1-6]. Theoretically, the patient collective can now act at the healthcare and research negotiating table between healthcare professionals, providers and researchers offering advice, engaging in co-operative efforts and criticizing project proposals. However, even though patient groups are endorsed as a negotiating party, this does not imply that

they are adequately equipped to identify relevant opinions among their own constituents, gather and oversee experience data and formulate a related patient vision. Patient groups, therefore, not only struggle with the question of whether they are perceived as a fully equal participant in negotiation, but also with how to usefully perform their role as a negotiating party.

This article concentrates on 2 questions: (1) to what extent are patients being involved as a group in health research, quality of care and related policy within The Netherlands? & (2) which criteria can be used to advance the patient perspective in a way that is complementary to the professional perspective within The Netherlands? When we speak of patient criteria, we refer to criteria that can be used by patient groups to bring in and assess the quality of care from the perspective of patients themselves.

Starting from the patient’s perspective implies, firstly, that patients are regarded as a useful source of experience and knowledge and, secondly, that this experience-based knowledge must be integrated into the policy-setting and decision-making process [7]. Any uncertainty, question, or issue originating from the patient experience then impacts the research, quality and policy process. Patient experience thus adds to the vision of professionals in these fields. Personal experiences can lead to experience-based knowledge *via* reflection and in turn to experiential expertise when this knowledge is tied to that of fellow patients. Experience-based knowledge is an important source for survival, ‘*joie de vivre*,’ problem solving and pleas for support [8]. Patient participation means that the patient is accepted as a partner in the knowledge acquisition process. This implies that patients are actively involved on an equal footing in the planning, execution and evaluation of research, quality and policy. The patient is also a player in the negotiations between healthcare suppliers and health insurance companies.

The ‘participation ladder,’ based on Arnstein’s ladder of citizen participation [9], indicates upward steps in the level of control that patients can have: from no say whatsoever to consultation, advice and cooperation and, ultimately, full control (Table 1).

Table 1 Patient involvement level and increasing influence

Level	Influence
Patient control	Patient party is the principal and has full control of content
Co-operation	Patients co-operate as equal partners with other parties and take decisions jointly
Advice	Patients offer advice when asked but take no group decisions
Consultation	Patients are asked for their opinion
No participation	Patients do not ask and are not asked

Based on our vision of patient involvement as a dialogue [10], patients would ideally be collaborative partners. This goes beyond the usual consultation (patients provide information) and advice (patients have no decision power), but does not constitute full control (all decision power is delegated to patients). In between is the status of ‘equal partner,’ the role of patients as a partner in the dialogue based on equality and the value of integrated, experiential and professional or scientific knowledge.

The purpose of patient involvement is twofold: (i) less medical paternalism and more democracy and (ii) as a contribution to the quality of process and outcome. Five arguments in favor of patient involvement are discussed in the literature. The first argument, which is most often heard, is the added content that patients may bring to the dialogue [11]. Their contribution can improve the quality of processes and results. A second argument is the

legitimacy of the decisions taken. This underlines the importance of more democracy. Since patients are direct stakeholders in healthcare, it is ideologically and morally proper to take their voice into account. Moreover, this ensures transparency of the decision-making process [12]. A third argument is that participation in decision-making impacts the empowerment of patients in a positive way [13,14]. A fourth category of arguments revolves around the likelihood of implementation of decisions taken. It is assumed that patient involvement leads to more commitment in the patient group and thus to the increased probability that decisions are actually implemented. The fifth argument relates to the efficiency and effectiveness of the healthcare system. Patient involvement provides patients themselves with a counterforce *versus* care suppliers and insurance companies [4]. In brief, patient involvement becomes a goal in itself when considering democratic decision-making and empowerment. In addition, it can be seen as a means towards substantive improvement, better implementation and greater efficiency, rather than to become a goal in itself. There is a risk of patient involvement degenerating into ‘pseudo-involvement,’ thus becoming a means to achieve the goals of other parties [15].

In theory, patient involvement in research, quality of care and policy is logical. Patients with a chronic illness and ‘people with disabilities’ and their organizations, however, emit signals that suggest the opposite. To explore the actual situation, we employed 2 methods: a literature search and interviews. The data resulting from these different methods were cross-checked and the issues found in the literature were presented to respondents to elicit comments.

Methods

Firstly, a literature search was conducted. Relevant search terms were established. These were: ‘patient involvement’, ‘influence and participation’, ‘citizenship’, ‘emancipation’, ‘right to have a say’, ‘patient movement’, ‘empowerment’, ‘patient perspective’, ‘patient and public involvement’ (PPI). The literature in journals on care, research, policy and wellbeing was then systematically searched using the search terms. In the sources identified, the references and internet links were searched until no further new relevant sources were found (data saturation). Because of the exploratory purpose of this study, the literature search was limited to the situation in The Netherlands and in the UK. It was focused on non-profit organizations and Government institutions. Business organizations, including the pharmaceutical industry, were excluded from the search. In total, 11 scientific and patient organisation journals and 6 international internet sites over the last 10 years were searched using the search terms (see Box 1 and Box 2).

Secondly, following the literature search, some 18 semi-structured interviews, each lasting approximately 1 hour, were conducted. Respondents were people from various patient and disability groups in their role of advisor

and co-operation partner in the time period 2008–9. The respondents all were representatives, participating on behalf of their respective patient group in health research, policy and quality matters. The selection of respondents took place as follows. Members of the Dutch Asthma Foundation, taking part in national committees, were asked to provide the names of patient representatives. The lead author also approached people in her own network who have been active as patient representatives for many years in various committees. After interviews with 9 respondents from 7 different patient and disability organizations, no further new information was obtained (data saturation). All interviews were recorded and transcribed. On the basis of quotes from the interviews, a ‘member check’ was conducted to obtain feedback from the respondents as to the correctness of the quotes. The collected data were thematically analyzed by content in an inductive way. The respondents were asked for their claims and concerns and any issues encountered during participation activities. The interview questions (both the original Dutch version and the English translation) are available from the authors.

Box 1 Journals searched using key terms

1. Medisch Contact;
2. Zorgvisie;
3. Zorg en Welzijn;
4. Nederlands Tijdschrift voor Geneeskunde;
5. Vraag in Beeld, Federation of Patients/Consumer Organisations in the Netherlands (NPCF);
6. Chronisch zieken en Gehandicapten Raad Nieuws;
7. Vilans, Kenniscentrum voor langdurige zorg, Nieuws;
8. Nieuwsbrief Participatie min Volksgezondheid, Welzijn en Sport (VWS);
9. International Alliance of Patients’ Organizations (IAPO) bulletin;
10. Health Policy;
11. Journal of Health Organization and Management Information.

Box 2 Internet sites searched using key terms

1. Patients Like Me (www.patientslikeme.com);
2. Involve (www.involve.org.uk);
3. People in Research (www.peopleinresearch.org);
4. The James Lind Alliance (www.lindalliance.org);
5. UK NHS Patient and Public Involvement (http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/patient_and_public_involvement.jsp).
6. National Institute for Health and Clinical Excellence (NICE) www.nice.org.uk.

Results

Quality of care

There are many ways for patients to be involved in the decision-making process in the healthcare sector. The patient’s voice is increasingly heard in the development of medical guidelines, for example, by becoming involved in development working groups. The opinions of patients are used more often to ensure greater transparency and quality of care. Examples of this include quantitative data collection for consumer input in a database of patients’ experiences (Originally called DIPEX, now available from Healthtalkonline) and publication of European Health Consumer Index (EHCI) ratings [8,16,17]. Healthcare institutions also use qualitative methods such as focus groups, mirror conversation and shadowing [18]. The European Patients’ Forum (EPF) has gathered these and other instruments for patients’ healthcare involvement in a ‘toolkit’ [19]. Both DIPEX and EHCI have Dutch derivatives: the Consumer Quality (CQ) Index and the former Institute for Healthcare Improvement (CBO) ‘toolbox.’ Also a set of methods for consumer involvement in health policy, healthcare and health research is available [20].

In The Netherlands, the introduction of the Social Support Act (Wmo) has increased the possibilities for local patient involvement significantly. Municipalities are now required to investigate customer satisfaction among people requiring care (consultation). This involves asking individual patients their opinion, which thereby provide information. As can be seen from Table 1, patients are not involved in the analysis of the data obtained. Involvement in the role of advisor is possible via the client councils. Patient organizations and federations of patient organizations mainly concentrate on the development and use of criteria for appraisal of the quality of care within improvement projects. General quality criteria for care of hospitals, aiming at professional competence, information, client treatment, supportiveness, independence, organization and accommodation have become the subject of scientific study [21]. Also, health research priorities, as seen by both patients and by researchers, are now being studied [22].

In summary, we contend that instruments for transparency and quality improvement, such as DIPEX and the EPF toolkit, do not focus on collective involvement of patients, but rather on individual *ad hoc* patient consultation. Advice by and co-operation with any patient group on a regular and structural basis often comes about due to coincidence - for example, as a result of someone happening to know a member of the patient group. The patient collectives and their national umbrella organizations, on the other hand, are busy with development of patient criteria for quality improvement that, aside from individual consultation, provide for possibilities of co-operation.

Table 2 Patient criteria found in literature, in use at public and private organizations, by type of criterion and domain

	Patients, disabled and elderly organizations	Healthcare institutions	Health foundations	Health research and development organization	Government organizations
Relevance to patients	Q , P	Q	R	R	P
Right to have a say	Q	n/a	R	R	n/a
Ethics and safety	n/a	n/a	R	n/a	n/a

Criterion types: Q = Quality of care, R = Health Research, P = Health policy, n/a = Not available

Health research and policy

Patients can exert influence on institutional policy in The Netherlands through client councils in health institutions. The introduction in The Netherlands of the Wmcz (Care Institution Clients Involvement Act) gives them extensive advisory rights, although it has attracted criticism. Patients can also influence Government policy. Patient representatives take part in various Dutch Government advisory councils. Furthermore, patient organizations are invited on an *ad hoc* basis to participate in parliamentary committees and express their views on policy decisions at the Ministry of Health. Finally, patients and their organizations have the possibility to change policy in a direction they wish *via* lobbying activities.

Hardly any criteria are available to assist the patient group with the appraisal of policy. Two criteria for health-related policy appraisal were found: joint development of policy and the policy document evaluation.

Upon request and on a commercial basis, experts offer advice to organizations on the client perspective in research projects and research policy. They also provide information on education. Criteria are described to evaluate research policy from a patient perspective, but these have as yet not been tested in practice. There are also possibilities for involvement in health research. Patients can discuss and take decisions in medical scientific research and increasingly do so, although their role is often limited to that of information provider or advisor [14]. An example of co-operation in research by a patient group is the set-up of an integrated societal research agenda for and with people suffering from asthma and chronic obstructive pulmonary disease (COPD), on behalf of the Dutch Asthma Foundation. Since the time of its inception, this foundation has continued to work with criteria from a patient perspective for the appraisal of research project proposals. These criteria are: (i) how and to what extent the results contribute to the needs of the target group (ii) is there an improvement of health and quality of life of the target group? (iii) what is the level of influence on the research proposal? (iv) can the target group have an impact on the execution of the project? (v) are results being fed back to the target group [23]?

Several health foundations apply the same criteria as the Dutch Asthma Foundation. The Netherlands Organization for Health Research and Development

(ZonMw), a Government health research finance organization, also compiled a list of patient criteria for the appraisal of research projects. This list takes into account the relevance and importance of the research project for the target patient group and whether (and if so, to what extent) the patient perspective is integrated into the planning and execution of the research [24].

In summary, we can state that patient involvement in health research and policy making is mainly at the information and advisory level and that the involvement is hardly structural and systematic. Co-operation with patients as a collective group is rare, apart from a few positive exceptions. Criteria for the appraisal of policy are scarce. Criteria for the appraisal of research are available at ZonMw and several health foundations. Whether they are fully operationalized and practicable for most patient representatives in their advice or partner roles remains questionable. A consideration of this question is presented in the next section.

The results of the literature search are shown in Table 2. Patient criteria found with different organizations and Government institutions are grouped by type of criterion (relevance, right to have a say and ethics and safety) and by domain (research, quality and policy).

Interviews

Our literature search shows that criteria for quality are fairly well operationalized. However, the patient and disability group respondents indicated that they do not use them in practice. Either the criteria are not readily available or, if they are, then the respondents are only vaguely familiar with them. The following quote illustrates this:

“No, there are no appraisal criteria; at least not that I know of. I use my intuition.” (Interview 3, male, visually impaired)

Patient representatives who are involved in development of clinical guidelines find it even more difficult. Several quotes illustrate this:

“More and more professionals act on behalf of the patient group in platforms and committees. As a patient, it is no longer clear on what basis an appraisal is done. That is a

Table 3 Summary of patient criteria for evaluating health research, quality of care and health policy

Criterion	Description
1. Relevance	<ul style="list-style-type: none"> -Improves the quality of life of patients (physical, social, mental) -Leads to better health -Takes other diseases into account (co-morbidity) -Improves the care of patients -Improves social participation -Leads to useful results for the patient group as it takes patient group properties into account, e.g., ethnicity, gender, age and socio-economic situation -There is a plan on how to implement the result in practice
2. Right to have a say	<ul style="list-style-type: none"> -The patient is a source of knowledge -Patients are equal negotiation partners, with a voice in research projects (definition, execution and evaluation), guidelines, quality requirements, choice assists with alternative treatments in care and policy -The patient group is recognized as citizens that must be listened to
3. Ethics and safety	<ul style="list-style-type: none"> -The least cumbersome means to achieve the goal -Safety of trial subjects -Explicit freedom of choice -Comply with and notify patients of the rules, codes of conduct, standards and values in medical trials on patients -Human dignity -Responsible and conscientious handling of complaints and informing the patient's own family doctor -Information in understandable language on results, side effects, aftermath, discomfort and absence from school, work or the social setting

pity and it is quite different from how it used to be; then we sat at the table ourselves as patients.” (Interview 6, male, Parkinson’s disease)

“I needed to search a lot on the internet just to understand the gist of the proposals.” (Interview 4, female, lung disease)

The problems expressed here relate to the fact that the patient group needs a minimum level of professional expertise to be able to join the discussion on the often complex process of developing a guideline [19]. On the other hand, too much professionalism has the disadvantage of being too close to the specialists and thus not being authentic enough. This also applies to representatives speaking on behalf of others.

Patient criteria for the appraisal of policy and research are, in the eyes of the interviewees, hardly operationalized or not known. Remarks about patient perspective tend to be abstract and vague. Criteria are difficult to apply in practice by the average patient or patient group. The following quotes clarify this:

“There is much demand for patient criteria among professional associations. They ask us: ‘Tell us how to approach patients. What do you consider good care?’ ” (Interview 3, male, visually impaired)

“Also my client group would like to do more appraisal of research, but they don’t know how.” (Interview 1, male, rheumatism)

Also, some of the issues that matter to patients are not found in the criteria, such as quality of life. Another quote to underscore this follows:

“Not the quality of care but rather the quality of life is the most important goal for patients. That ought to be the starting point from which research and policy need to operate.” (Interview 4, female, lung disease)

Respondents also explicitly mentioned several criteria on ethics to be missing. This concerns the availability of insurance for patients who are test subjects in clinical trials covering effects on illness, work, or social commitments. Also, they mention access to written information in understandable language about the choice whether to participate, plus sufficient time to consider and discuss before deciding to accept or not. Finally, they consider feedback of the intermediate or final results of the project to test subjects and patient groups as important in relation to human dignity. Again, a quote to illustrate this follows:

“It is so easy to say that the test you are subjected to is harmless and that there is medical support, but if your ailment gets out of control it will take more than just some antibiotics. You may end up being on sick leave for weeks or even months and that you don’t want.” (Interview 5, female, lung disease)

The respondents furthermore missed criteria on patient empowerment, such as whether the patient group is a partner in the project committee, whether the patient group is involved in project definition and evaluation and whether the project sufficiently considers the diversity within the patient group in terms of gender, ethnic background, age, socio-economic circumstances and other diversity aspects. One patient representative says about this:

“The input that patients provide is entered into the process, but does not really have an effect. It’s like getting a bit of

mustard with the last bite of the meal.” (Interview 2, female, chronic headache)

Finally, criteria on relevance were felt to be missing. The criterion ‘whether the project objective is relevant for the patient group’ was too general, vague and abstract for the respondents to be able to say anything specific about it. The respondents preferred to concentrate the relevance criterion on the question: ‘can the project upon reaching its goal improve the quality of life for the patient group in relation to their physical, social and mental limitations?’

In summary, we contend that there are hardly any patient criteria for appraisal known to patient representatives and their patient groups. The few that exist are difficult to use, vague, abstractly written and poorly recognized. In other words, they are hardly available or operationalized.

Analysis

The literature search on quality of care, policy and health research resulted in a set of largely common issues. The results from the respondent interviews underline and confirm these results. Also, the lack of a systematic appraisal method, available to patient groups, was confirmed. Both the literature search and the interviews indicated that the issues identified show 3 major areas of concern for patients and people with a disability: (i) relevance; (ii) right to have a say and (iii) ethics and safety.

Hence, these are the 3 criteria categories by which patients judge both quality of care and health research, so a new concept is proposed: a patient criteria list. The criteria were incorporated in the patient appraisal criteria list proposed in Table 3. These criteria must be sufficiently met in order to realize patient involvement.

Discussion

The research on involvement of patient representatives at the negotiating table shows that patients are mainly consulted on an individual and *ad hoc* basis in The Netherlands. Advising by patients and co-operating with patients as a collective group is coincidental at best. There is little awareness among active patient representatives of the few existing appraisal criteria from the patient’s point of view. This requires – on first analysis – better information and communication.

The few currently available criteria are found to be unclear and impractical, however. Hence, patient participation is not effectively supported and non-indigenous patients with language issues cannot even use the criteria. The patient’s voice is therefore not sufficiently heard in the healthcare quality and health research areas. Therefore, more effective tools for appraisal by patients are also required, the proposed concept for a criteria list being one of these. To better equip patients in their role as a negotiating party, it is desirable to arrive at a more refined and recognizable list of patient criteria for quality, health policy and research. The initial list of patient criteria as

developed in this study comprises 3 main sections: relevance, right to have a say and ethics and safety. This list needs further refinement and validation in future studies. The list may be compared to internationally available patient criteria for health research, such as the IAPO toolkit for patient organizations [6]. In addition to addressing patient safety, this includes criteria for patients subjected to medical trials, advocacy and partnership. After the comparison, the criteria list may be adapted and re-scoped also to envelope specific areas and groups, in close consultation with patients.

Apart from developing criteria, it is also important to increase the skills of patients in addressing their new task. This empowerment is necessary since patients often feel insecure about their contribution and added value, especially when new in their role. Moreover, research and policy are complex domains for the average patient and patient representative. The Dutch organization Tools2use, a foundation for empowerment through expertise of the chronically ill or people with disabilities, works on advice, support and training of experience experts [25]. Similar initiatives in the UK (Involve, NICE) have resulted in guidelines for patient groups and members of the public to appraise research grant applications, healthcare policy and guidelines on quality of care [18,26,27]. Describing examples that illustrate the problems can be of help to inform patients and other parties and thereby contribute to patient empowerment.

Finally, it is not just a sound democratic principle to employ patient criteria so that the voice of patients is clearly heard. Patient groups have a profound knowledge of their own situation and have no interest other than to defend the quality of life and care of individual patients. This constitutes an argument to employ the patient group itself in the negotiation process, rather than having external organizations act on behalf of patients, given that these tend to mix their own interests with those of patients.

Conclusion

Between the *ideal* of patient groups as equal partners at the negotiating table and the actual *reality*, there is still a wide gap in The Netherlands. Although patients increasingly attempt to negotiate health with other stakeholders, in practice virtually no systematic assessment method from the patient’s perspective is available. The few criteria that exist for patients are poorly operationalized and abstract and it is unclear what significance they have. They are therefore difficult to apply and offer little sense of direction to the patient representative or council.

To satisfy the expectations of patients, more support and greater efforts are required. Here, the systematic development and validation of patient criteria, increasing the skills of patients *via* increased awareness and training and building on successes such as good examples of co-operation, is of great importance. Patients need a set of criteria that is recognizable, workable and complete. By developing and validating criteria systematically with patients, the gap between current practice and their desired

role as an equal negotiation party is likely to be reduced. An instrument, such as a criteria list, makes negotiation easier for patients and it enhances the quality of the outcome of their participation.

The proposed concept of a patients' criteria list is expected to be of practical use to many patients in many countries.

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