Including citizens in institutional reviews: expectations and experiences from the Dutch Healthcare Inspectorate

Samantha A. Adams PhD,* Hester van de Bovenkamp PhD* and Paul Robben PhD†

*Assistant Professor, †Professor, Institute of Health Policy and Management (iBMG), Erasmus University Rotterdam, Rotterdam, The Netherlands

Correspondence

Samantha A. Adams Institute of Health Policy and Management (iBMG) Erasmus University Rotterdam Woudestein J8.39 Post Office Box 1738 3000 DR Rotterdam The Netherlands E-mail: adams@bmg.eur.nl

Accepted for publication

16 August 2013

Keywords: Citizen/patient participation, Health Inspectorate

Abstract

Background Recent changes in the structure and policy context of Dutch health care have placed the issue of citizen participation high on the agenda of the Dutch Healthcare Inspectorate (IGZ), which conducts quality and safety reviews in medical practices and health-care institutions. With a few exceptions, the potential role that citizens can play in the regulation of health-care institutions is overlooked in research on patient/citizen participation in health care.

Objective This research addressed the following question: What are the (political) expectations for increasing citizen participation in health-care regulation and how do these compare to regulators' expectations and experiences in practice?

Design Because of the largely explorative nature of this study, we used qualitative methods (document and web analysis, focus groups and interviews) to answer this question.

Results Our study shows that inspectors already have experience with participatory formats that lead to important information. There are three areas where the IGZ is currently increasing citizen participation: (i) providing individuals with information about inspectorate processes and activities, (ii) including patients as sources of information, and (iii) formally reviewing how citizen participation is ensured by health-care institutions. In situations where the patient has the clearest overview of the whole care trajectory, intensive methods of participation deliver valuable information.

Conclusions It is important to target participation activities and to capitalize on existing opportunities and activities, rather than creating participation activities for the sake of participation. In this regard, further research on the effectiveness and efficacy of different participatory strategies is necessary.

Introduction

Western European attention for increasing and improving citizen participation in the healthcare sector has steadily increased over the last thirty years. Citizen participation in health care is generally understood as both individual and collective patient participation. At the individual level, participation is focused on shared decision making during a medical encounter or on facilitating patient choice of providers, insurers, services, etc. At the collective level, patients are asked to contribute in decisionmaking processes at national and local levels, including developing guidelines or policies, setting research agendas and improving the quality of care.

In the Netherlands, there are many opportunities for patients to participate, with formalized structures for participation, for example, the institutional client's council, being required by law. Such laws reflect a common policy assumption that formal participatory structures enable more democratic decision making, provide institutional legitimacy and create a health-care system that better meets the needs of the individual patient.² Patient experiences are framed as important supplemental knowledge to that of managers and professionals. Increasingly, this information is actively sought by various institutions and organizations that have a stake in health care. 1,3,4

As is further outlined below, recent changes in both the structure of Dutch health care and the policy climate of the Netherlands have explicitly placed the issue of citizen participation on the agenda of the Dutch Healthcare Inspectorate (IGZ) – an agency within the Ministry of Health, Welfare and Sports.⁵ The IGZ guards the quality and safety of care and enforces 25 laws. IGZ uses three methods of regulation*: theme-based regulation, regulation in response to reported incidents and riskbased regulation using indicators. Regulation covers a broad spectrum, ranging from professionals and health-care institutions to pharmaceuticals, blood transfusion services medical devices.^{6,7}

With a few exceptions, 8-11 the potential role that citizens can play in the formal inspection reviews of health-care institutions that are conducted by inspectorates/state survey agencies is overlooked in research on participation in relation to health care. This article, based on a study of citizen participation in inspectorate review processes in the Netherlands, contributes to filling this gap. Knowledge about this subject is important given the international trend towards including citizen input in inspectorate reviews 11,12 and the role of citizen input in high-profile cases such as the recent Mid Staffordshire enquiry. 13,14 As discussed below, expectations for such participatory practices are high.

In this article, we discuss the proposed use of citizen participation for the purposes mentioned above. We address the following research question: What are the (political) expectations for increasing citizen participation in health-care regulation and how do these compare to regulators' expectations and experiences in practice? After explaining the methods used in this project, we give some background information on recent changes in the Dutch policy landscape, especially in relation to the IGZ. We then outline the (contested) goals of citizen participation and give an overview of three areas where IGZ is increasing participation. In the discussion, we identify the lessons learned in this study and argue the importance of targeting participation activities and capitalizing on existing opportunities and activities, rather than creating participation activities for the sake of participation.

Methods

Because of the largely explorative nature of this study, we used qualitative methods: document and web analysis, focus groups and

^{*}The term used to refer to work of national inspectorates (regulatory agencies) varies per country. With one exception in the translation of an agency name, we follow the English Care Quality Commission (CQC) in this study, referring to this work as 'regulation' or 'regulatory practice'.

interviews. To get an overview of the political context of the aforementioned changes, we conducted a document and website analysis. We began with internal documents from the IGZ, including policy documents, plans to be implemented and notes from meetings where experiences with citizen participation had been discussed. We reviewed reports from the Dutch Ministry for Health, Welfare and Sport (Min-VWS) and relevant items from the record of the second chamber of Dutch Parliament. Both sets of documents spanned a timeframe from 2009 to 2011. We reviewed the websites of Dutch Inspectorates from other policy sectors (Education, Finance, Food/Consumer products and Youth Affairs) as preparation for interviews (see below) and to get a feel for how they represented themselves in relation to their respective citizen publics. We accepted any documents provided during the interviews that provided insight into experiences with citizen participation in other sectors.

To understand opinions of and experiences with citizen participation within the IGZ, we held four focus groups in October and November 2011, each with approximately eight participants, all of whom were employees of the IGZ. Participants could volunteer to participate, but were divided into groups according to their function or assigned inspectorate programme.† This ensured that we had the best possible representation of both the programmes and divisions, such as the newly created Central Information Office (for reporting of incidents) and the Department of Research and Innovation, in each group. During the focus groups, we discussed the following: definition of (citizen) participation, desirability of increased citizen participation in regulatory reviews, examples and experiences from current practice and necessary preconditions for actively stimulating more citizen participation in this sector.

Concurrent with the aforementioned activities, we conducted semi-structured interviews (n = 19). Face-to-face interviews were held with IGZ employees, inspectors from the policy sectors mentioned and organizations such as the Dutch Patient and Consumer Federation (NPCF), which represents the interests of patients at various policy levels. The purpose of these interviews was to get an impression of the different opinions on increased citizen participation and ideas on how to concretize this goal in practice, to learn about current and past experiences and to outline the perceived advantages and disadvantages of these approaches. Because the purpose of our study was to gain a better understanding about the ideas and experiences of the Dutch Healthcare Inspectorate itself, we did not include individual citizens in our response group.[‡]

All face-to-face interviews and the focus groups were recorded and transcribed verbatim. All documents and transcripts were reviewed independently by each researcher. A combination of concepts from the literature and concepts emerging from the data (deductive and inductive coding, respectively) was used to select and categorize analytical themes. For this article, all quotes were translated from Dutch to English by the first author, a native speaker of English with certification of Dutch as a second language. The translations were verified and checked for proper capture of nuance, diction, etc. by the second author, a native Dutch speaker.

Results

In this section, we first focus on the background and the expectations of participation of actors in the regulatory context. We then discuss inspectors' experiences with participation and their opinions of incorporating citizen participation in daily practice.

[†]The Dutch Healthcare Inspectorate structures its work in ten programmes: Public Health, Disease Prevention, Primary Care, Specialist Somatic Care, Disabled Care, Elderly/Geriatric Care, Home-based Care, Pharmaceuticals, Mental Health and Medical Technology.

[‡]The Dutch organization NIVEL has since conducted a study about the public image of the IGZ that also included a survey of individual citizen opinions. 15

Dutch policy context: the crucial role of citizens in assessing health-care quality

Since the 1980s, Dutch health care has been incrementally reformed into a system with a focus on demand drive care. 16 This reform process culminated in the 2006 introduction of the National Health Insurance Act, which shifted the health-care system from a 'social versus private insurance' model to a regulated marketbased model.¹⁷ This change emphasized the underlying philosophy that health care should be attuned to individual patient preferences and that patients should be given an active role in their own care process. The opportunity for patients to be more active has become an important aspect of what is defined as good quality health care. Such broad-sweeping systemic reform inevitably influences the work of the Inspectorate, whose job it is to review the quality of health care: in addition to their existing tasks, regulators must now also check how health-care providers enable patient participation and facilitate the provision of demanddriven care.

The introduction of regulated competition increased policy emphasis on transparency. Ever prevalent calls for transparency depart from the assumption that publicly disclosing information about performance will signal points for improvement and lead to concrete change, for example through mechanisms such as performance indicators and patient choice. 18 To publicize performance indicators and give patients access to other information that facilitates choice, various parties have developed web-based information platforms. Increasingly, patients are also expected to contribute information to these sites, for example by publishing their experiences with an institution, professional or medication.^{3,19} Citizens are therefore not only users of quality information; they become sources of quality information, as well. This brings us to a second way that the focus on an active role of citizens in the health-care system can affect the work of the Inspectorate: it is expected to make more active use of citizens as sources of information because they potentially provide relevant signals about the quality of care.

Although health-care system reforms have clearly put citizen participation on the agenda of the inspectorate in several ways, the push for citizen participation has also arisen from political pressure placed on the IGZ after questions were raised in government and the media about the legitimacy of its work. The need for the IGZ to be more accountable for its actions received national attention in a 2009 report from the National Ombudsman§ that poignantly named the inspectorate a 'paper tiger'. The Ombudsman report emphasizes that the citizen-as-patient is always dependent in the health-care setting. For this reason, government institutions must protect citizens, defend their rights and ensure that they are taken seriously. The IGZ is a crucial player in defending these rights, yet the Ombudsman report asserts that it has, until now, insufficiently fulfilled this task and failed to strengthen the position of patients. Most notably, the report criticizes the failure of the IGZ to take citizen complaints seriously as signals of deeper problems and to communicate with citizens effectively about these complaints. The Ombudsman asserts that the IGZ does not value citizens as a source of information, despite the fact that patients and their families have the best view of daily care practice. 20,21

This critique also became an issue of debate in the second chamber of Parliament.²² Similar to the National Ombudsman report, Parliamentary debates questioned whether the IGZ was an organization that could be taken seriously enough to affect the quality of care. They made similar assumptions about the

[§]The Office of the National Ombudsman is guaranteed by the Dutch Constitution and regulated under the 1981 National Ombudsman Act and 1992 Dutch General Administrative Law. The National Ombudsman is an independent, neutral institution that helps Dutch citizens who experience problems with government organizations (http://www.nationaleombudsman.nl/english). The National Ombudsman responds to complaints and has the authority to launch its own investigations. Given the authority of the National Ombudsman, reports issued by this office carry great national political weight.

importance of information that patients can provide and how this should be used by the IGZ. These debates resulted in the motion for and approval of the creation of a Central Information Office for reporting incidents,²³ which increased political pressure on the IGZ to make more active use of individual citizen reports and complaints in regulatory practice. This policy decision complicated practical matters in that it muddied the waters of responsiindividual (patient) for handling complaints. Legally, a given health-care institution is responsible for handling individual complaints about the quality of care in that institution and every institution has an internal body to which patients can turn when necessary. Responding to such complaints is not, however, one of the formal legal responsibilities of the IGZ. However, as is further discussed below, the politically driven creation of a Central Information Office at the IGZ for patients to report incidents also created expectations in the general public about how the IGZ would handle these complaints that did not always align with the practice of the IGZ.

This context description makes evident that citizens are expected to play a crucial role in the assessment of quality of care in the Dutch health-care system. Involving citizens is considered important for the following reasons: ensuring quality of care, improving regulation practice and creating accountability. Moreover, this means that citizen participation in relation to regulatory practice is multifaceted. Assessing patient participation within health-care institutions as a quality measure, including citizens as information sources during regulatory review, protecting citizens' rights and accounting for regulatory activities all figure into the debate. In the subsequent sections, we examine how this translates into practice, in terms of expectations for and experiences with citizen participation.

Goals of participation according to the inspectorate

As a result of the changes in the health-care system and related political pressure, the IGZ has begun addressing the subject of citizen participation, for example, by establishing a Central Information Office and including citizen participation as a pillar in its 2012-2015 longterm plan.²⁴ It also conducted an internal study of possible avenues for concretizing citizen participation in practice.²⁵ Employees of the IGZ must deal with this external and internal pressure and are expected to find new ways to relate to citizens.

When asked about expectations for increasing public participation, IGZ employees identified several possible goals of increased citizen participation, which partly reflect the ideas underlying the public debate. One goal is improving institutional review, whereby the patient indeed becomes a valuable source of information about aspects of demand-driven care (or lack thereof), or other signals about quality that an inspector might not see during a regular inspection that is focused on health-care professionals.

Patients have a perspective about their own 'life and limb'. Does the food taste good, is the nurse nice, are they on time so I don't have to wait too long, am I woken up on time... my breakfast was too late, so I'm not hungry for lunch, I had to wait for 45 minutes, which I didn't appreciate... really basic things, but that's what patients find important. (Respondent IGZ 6)

As we further show below in the lessons from practice, when patients are included as information sources, they are indeed able to give information about the quality of care. The information that, for example, chronic patients can provide goes beyond the expected comments on the 'softer' aspects of care to include signals about the technical quality and safety, which is relevant to the work of the regulator.

A second goal that inspectors mention is legitimizing decision-making processes. Involving citizens and being more transparent about the IGZ's work gives a sense of accountability. A third, related, goal is improving the image of, and increasing trust in, the IGZ. Inspectors feel that involving citizens more might help silence the critique of actors in their regulatory context.

Questioning the drive towards more participation

Although the respondents in both the interviews and the focus groups generally favoured increasing citizen participation, they also questioned the policy shift towards more citizen participation. They voiced several arguments to substantiate this critical view.

One primary concern was that participation is positioned as a goal in and of itself, whereby participatory activities are mostly added to other activities 'for the sake of participation', or just to respond to the aforementioned external political pressure. They were concerned that participation derived from political pressure might not necessarily be better for either the inspectorate or the citizens.

The problem is, actually, that the Ombudsman has his say, then the politicians have their say and then you have something like the Central Information Office that is politically driven. (Respondent IGZ 8)

At a certain moment, somehow, it seems like a leaf in the autumn. No one knows where it comes from, but it blows in very slowly. And the moment it lands, apparently, you must do something about it. (Respondent IGZ 10)

A second concern was that the specific plans dictated by the Dutch Ministry of Health, Welfare and Sport would place the IGZ in an awkward position in relation to citizens. Primarily, they were worried about the IGZ's ability to manage the expectations on an individual level that these new structures and activities create.

And then it gets complicated. Citizens expect that we'll judge in their favour and that they have a right to some form of retribution, but that's not our job. My greatest fear is that we'll start creating expectations that we're unable to manage and also cannot meet. That's also a concern of many inspectors. (Respondent IGZ 6)

This concern is expressed specifically in relation to the new Central Information Office, whereby the National Ombudsman and Parliament expect the IGZ to be more effective in responding to individual complaints. However, employees stress that their job is not to handle individual cases, but to protect the quality of care in general, which they do through established review processes. While citizen input can be important in these processes, it is necessary to ensure that individuals do not expect the IGZ to solve individual problems. Moreover, respondents note that the IGZ has insufficient capacity to respond to individual cases.

A third concern was about the assumptions underlie the debate. that public approaches to citizen participation suggested in political circles, such as the creation of the Central Information Office, depart from a certain level of distrust in both health-care organiand the inspectorate. participation is accompanied by the suggestion that only individual citizens can tease out what is 'really' happening in daily practice because the IGZ has an insufficient view of quality issues. This position fundamentally conflicts with that of many people working for IGZ; they act on the assumption that care professionals are intrinsically motivated to deliver the best possible care. The inspectors recognize that trust, in both professionals and institutions, is an important part of regulatory practice.

Although respondents identify the added value of participation, they nonetheless raise important concerns that result from conflicting ideas about good regulatory practice. This makes the issue of when and how citizen participation can best be put into practice crucially important. From the experiences with participation of the IGZ so far lessons can be drawn about how participation can be put into practice in such a way that the concerns identified in this paragraph are mitigated. We will turn to these in the next section.

Lessons from practice: when and how to include citizens

From the experiences of our respondents lessons can be drawn about when and how to let citizens participate. One important step is categorizing forms of participation. Respondents from the IGZ identified three distinct areas where participation should be considered in their work. The first area, related to the idea of transparency, was external communication, because the IGZ must provide clear and timely information about inspectorate processes to citizens. A second area, also evident in the previous sections, is regulatory review, where patients become sources of information. A third area is the change in health-care practice mentioned above: formal review of how institutions ensure citizen participation.

Information about inspectorate processes and activities

The public debate focuses on the IGZ's failure to live up to expectations that it protects citizens from poor quality health care. Although the solution of being more responsive to individual complaints as proposed by the Ombudsman and Parliament is not always shared internally, respondents do agree that they could improve their work by explaining more clearly to citizens how IGZ works and what citizens can expect. Moreover, they agree that communication is important in cases where individuals do make a complaint. Sharing information about the IGZ stems less from the accountability goal as might be expected but more from the goals of expectation management and building trust.

In the Elderly/Geriatric Care Programme at this moment, we have a number of rather notorious complainers. These are all situations that have been blown out of proportion. We know that for each situation there was a bottom line to the story that was important, but that the patients weren't taken seriously at the time. (Respondent IGZ 6)

Using language citizens can understand and not falling back on inspectorate policy jargon is, according to our respondents, the key to doing this well.

We're usually restrained in explaining where the limits of our task lie and we clamp down on that distinction, even though it is often easy enough to step over the line. I think we should do that more often. A prime example is of course not dealing with individual complaints. (...) I sometimes tell callers that concerns over care quickly sound serious, but at the same time I explain to them that if you have a problem with your neighbor, it is better to discuss that with the neighbor in question and not with another neighbor. People seem to understand it when you phrase it that way. (Respondent IGZ 5)

Including citizens as information sources

The role of citizens as information sources is recognized both in the public debate and by inspectors themselves. The results show that this role takes various forms in practice; including using complaints or reports of citizens as a starting point, as was emphasized by the Dutch Ministry of Health, Parliament and the Ombudsman. However, in the opinion of respondents, the input of citizens can also be used in other ways during reviews. Inspectors have had positive experiences, for example using web-based surveys and interviews with patients to get better insight in the delivery of care for chronic respiratory patients.

But why we did that here, for chronic respiration, and also with infuse pumps, was because in a diffuse field with various issues, where there are many caregivers involved, we knew that the responsibilities might not be completely clear and there were no guidelines or norms. And this was also a group of patients that tried very hard to stay in control - a large number of patients that organize their care through their personal budgets and have lots of contacts with health professionals. Who are the experts when it comes to safety, quality, or clarity in agreements? The patients. (Respondent IGZ 2)

The Integrated Supervision of Youth Affairs (ISYA)¶ has used lay inspectors in their work. Older teenagers are trained to talk to other youth in the social care system in order to

ISYA is a partnership initiated in 2003 between the IGZ, Education Inspectorate, Inspectorate for Youth Care and Inspectorate for Public Order and Safety. The Inspectorate for Social Affairs and Employment joined in 2005. The partnership seeks solutions to social problems that cannot be addressed by a single organization or sector. Since its inception, ISYA has conducted thirty joint inspections utilizing methods that involve all stakeholders to create solutions that match youth needs.

tease out what they struggle with in practice and how this care can be improved. This works well because young people often do not easily talk to official inspectors, who are part of 'the system' that these youth do not trust; talking to someone who has been in the same situation is easier. However, inspectors also indicate the need to carefully consider when to use this method, because it does not always transfer to other situations. Using lay inspectors to interview care professionals, for example, did not work well in practice because professionals largely tended to ignore the lay inspector and kept talking to the formal inspector. Also, lay inspectors need to be trained in order to fulfil this task, which requires a considerable time investment of both the regulatory office and the lay inspectors themselves.

Another method of participation that respondents find works well is talking to patients or clients during regular site visits. This is less time intensive than the methods mentioned above and delivers valuable information.

If you get down on your knees next to their bed, so to speak, then you hear things. But I have also known inspectors who are totally incapable of taking such an approach. (FG 1)

This quote indicates that involving citizens properly also requires certain skills from inspectors. The language used to talk to patients is important, as is finding ways to translate patient input into information inspectors can use in their reports, which often proves difficult in practice.

The problem, I think, is that we need to be able to check it off on a list, because in the end, we always want a measurement. And that is always the dilemma with indicators, too. Then we start measuring all sorts of things because we need to be able to have a uniform measurement, while a patient just wants to be treated properly. And what is proper? The soft aspects that are so difficult to measure. (FG 2)

The IGZ could also use methods of participation already in place in the health system, such as information provided by client councils, patient organizations or on social media. Although respondents see the potential of this, they also point out related difficulties. such as representativeness. Persons active on social media, in client councils and patient organizations may not represent (the interests of) the patient population at large.

And then there is one other thing, what is the patient association? We ran into the problem that the Dutch Patient and Consumer Federation doesn't actually speak for the patient - they're just the policy people. (FG 2)

These experiences illustrate several ways to organize citizen participation during supervision activities, some of which may be useful in specific situations, but nonetheless contain certain disadvantages. This suggests the importance of carefully considering when and how to use citizens as sources of information.

We should not incorporate citizen participation in all research just because that's currently fashionable. No, it should come from the purpose of the research and the questions we want to have answered - if we follow that route then it will actually have added value. (Respondent IGZ 2)

Reviewing institutional guarantees of citizen participation

The third area comprises how health institutions ensure citizen participation as part of providing good care. This often remains unaddressed in regulatory practice. However, respondents do see the added value of this, both as a means to deal with external pressures and because patient participation in health-care institutions is an integral part of what is considered to be quality care. Moreover, it could be a means to limit the pressure currently felt by the IGZ to organize citizen participation itself and place this responsibility in the hands of health-care institutions, where - according to some of our respondents - it belongs:

I think the hospitals should arrange that better themselves. Not us. The hospital is responsible for care and thus needs to learn from patient experiences. (Respondent IGZ 9)

These results show that the multifaceted nature of participation can be used by the inspectorate to incorporate demands for participation in such a way that it can mitigate the concerns about participation which, in the perception of our respondents, would prevent the inspectorate to perform their task of reviewing quality of care well.

Discussion

In this article, we have shown that the issue of citizen participation, which has increased in importance in health care over the past decades, also influences the practice of healthcare regulation. The Dutch case presented here follows similar developments in other countries, such as Australia, 8,9 Ireland 11 and England, 12, 26 where citizen input is increasingly included in inspectorate reviews. Regulators recognize the potential added value of participation for reasons identified in the public debate, and the effectiveness of participation has also been shown in the literature.8 There are nonetheless concerns about how increasing participation at various levels influences the nature of the regulatory task. The Dutch case not only teaches several lessons in this regard, but also raises more overarching issues that are interesting for an international audience. We first outline said lessons from the Dutch regulatory context and then reflect at a more general level on the underlying policy assumptions that are influencing regulatory practice.

First, because it is difficult to organize participation well, 27-29 including citizens in a given process should be carefully considered per situation, explicitly questioning if and how participation could be beneficial for supervision in that situation.

Second, the distinction we made between areas of participation which are related to the different goals of participation, (i) providing citizens with information about inspectorate processes and activities, (ii) including citizens as information sources and (iii) reviewing institutional guarantees of citizen participation, could be a relevant first distinction to make when deciding on the how question.

Third, within the aforementioned categories, the how should be elaborated further; especially, the second category can be shaped in numerous ways in practice. Successful methods identified in this study include talking to patients during regular visits which can provide inspectors with important information.⁸ This does not take much time from either inspectors or participants and draws from the everyday experiences of patients, which is considered to be an important additional perspective to that of professionals and inspectors. In certain situations, such as when the patient has the clearest overview of the whole care trajectory, intensive methods of participation also prove to deliver valuable information.

A fourth lesson is that differentiating areas of participation can also be useful when trying to align the external political goals with internal ideas about what constitutes good regulatory work. For example, providing citizens with information can be put into practice to ensure accountability and at the same time to manage expectations. Also, concerns about participation becoming a goal in and of itself can be mitigated by focusing more on the participation possibilities of patients within specific settings, such as the health-care organizations in the review process. By aligning goals, Inspectorates can give citizen participation a more explicit place in health-care regulation without taking away from the complexities of both participatory and regulatory practice.

Finally, more research into what does and does not work is needed to further inform decisions about when and how to let citizens participate in inspection work. It is therefore important for regulators to couple internal and external evaluation on attempts to implement participatory mechanisms. Inspectorates can also engage citizens in identifying priority areas and developing such evaluative processes. Incorporating citizens in earliest phases of research will not only contribute to the growing body of evidence about what does/not work in practice, but will also feed back into

meeting the overarching political goals (such as legitimacy, transparency and accountability) that are so concretely influencing practice in various health-care arenas.

At a more general level, this case gives cause to reflect on how political goals translate into specific practical contexts. We began with the question, what are the (political) expectations for increasing citizen participation in health-care regulation and how do these compare to regulators' expectations and experiences in practice? There is an obvious tension between both political and regulatory actors' expectations for participation and the regulators' actual experiences in practice. Although accountability and transparency are lofty goals, the specific policy solution that is proposed to achieve these (i.e. 'more' participation), carries with it certain risks. If participation is increased merely for the sake of participation, information gained through contributions to participatory processes can too easily be ignored.30 In this case, 'citizen participation' becomes little more than a ritualized aspect of review, rather than a real attempt to engage citizens and effectively use the valuable input they can deliver. In responding to external (political pressures) to increase citizen participation in health-care regulation, inspectorates should therefore take the time to reflect on how activities to engage citizens align with internal goals established practice.

References

- 1 Van de Bovenkamp HM. The Limits of Patient Power: Examining Active Citizenship in Dutch Health Care. Rotterdam: Erasmus Universiteit Rotterdam. 2010.
- 2 Van der Kraan WGM, Meurs P, Adams SA. Effectieve Medezeggenschap. Een Verkennend Onderzoek Naar Effectieve Vormgeving van Medezeggenschap van Clienten in Algemene Ziekenhuizen. Rotterdam: iBMG, 2008.
- 3 Adams SA. Sourcing the crowd for health services improvement: the reflexive patient and "share-yourexperience" websites. Social Science and Medicine, 2011; 72: 1069-1076.

- 4 Ziebland S, Coulter A, Calabrese JD, Locock L. Understanding and Using Health Experiences. Oxford: Oxford University Press, 2013.
- 5 Robben P. Burgerperspectief van de IGZ. Utrecht: IGZ, 2011.
- 6 Hout FAG, Nienhuis E, Robben PBM, Frederiks BJM, Legemaate J. Supervision by the Dutch Healthcare Inspectorate. European Journal of Health Law, 2010: 17: 347-360.
- 7 Tuijn S, Robben PBM, Janssens FJG, van den Berg H. Evaluating instruments for regulation of health care in the Netherlands. Journal of Evaluation in Clinical Practice, 2011; 17: 411-419.
- 8 Braithwaite J. Makkai T. Braithwaite V. Regulating Aged Care. Ritualism and the New Pyramid. Cheltenham: Edward Elgar, 2007.
- 9 Braithwaite J, Makkai T. Can resident centred inspection of nursing homes work with very sick residents? Health Policy, 1993; 24: 19-33.
- 10 Scourfield P. A critical reflection on the involvement of 'Experts by Experience' in Inspections. British Journal of Social Work, 2010; **40**: 1890-1907.
- 11 Health & Social Care Regulatory Forum. Framework for Public and Service User Involvement in Health and Social Care Regulation in Ireland, 2009. Available at: http://www.rpii.ie/RPII/files/62/ 62f874c3-65e6-4b93-b923-695a3c8ba9bf.pdf.
- 12 Care Quality Commission. Voices into action. How the Care Quality Commission is going to involve people. London: CQC, 2010.
- 13 Francis R. Mid Staffordshire NHS Foundation Trust Public Inquiry. Final Report. London: The Stationery Office, 2013. Available online: http:// www.midstaffspublicinquiry.com/report, accessed 11 march 2013.
- 14 Hawkes N. How Cure the NHS became the true professionals at Mid Staffs. BMJ: British Medical Journal, 2013; 346: f930.
- 15 Brabers A, Reitsma M, Friele R. Het beeld van zorggebruikers over de Inspectie voor de Gezondheidszorg. Utrecht: Nivel, 2013.
- 16 Helderman JK, Schut FT, van der Grinten TED. van de Ven WPMM. Market-oriented healthcare reforms and policy learning in the Netherlands. Journal of Health Politics, Policy and Law, 2005; 30: 189-210.
- 17 Enthoven AC, van de Ven WPMM. Going Dutch: managed-competition health insurance in the Netherlands. New England Journal of Medicine, 2007; **357**: 2421–2423.
- 18 Robben P. Toezicht in een glazen huis. Rotterdam: Erasmus University Rotterdam, 2010.
- 19 Adams SA. Post-panoptic surveillance through healthcare rating sites: who's watching whom?

- Information, Communication & Society, 2013; 16: 215-235.
- 20 Nationale Ombudsman. De Inspectie voor de Gezondheidszorg: Een Papieren Tijger? Den Haag: Nationale Ombudsman, 2009.
- 21 Nationale Ombudsman. Onverantwoorde Zorg UMCG, Onverantwoord Toezicht IGZ. Den Haag: Nationale Ombudsman, 2011.
- 22 Tweede Kamer Handelingen, 71:61052010.
- 23 Tweede Kamer. 24 170. no. 109. 2009-2010.
- 24 IGZ. Meerjarenbeleidsplan 2012–2015, Voor Gerechtvaardigd Vertrouwen in Verantwoorde Zorg (II). Utrecht: IGZ, 2011.
- 25 Blok H. Burger en Toezicht. Utrecht: IGZ, 2011.
- 26 Prosser T. The Regulatory Enterprise. Government, Regulation and Legitimacy. New York: Oxford University Press, 2010.

- 27 Van de Bovenkamp HM, Trappenburg MJ. Reconsidering patient participation in guideline development. Health Care Analysis, 2009; 17: 198-216.
- 28 Légaré F, Boivin A, van der Weijden T et al. Patient and public involvement in clinical practice guidelines: a knowledge synthesis of existing programs. Medical Decision Making, 2011; 31: E45-E74.
- 29 Epstein S. Patient groups and health movements. In: Hackett EJ, Amsterdamska O, Lynch ME, Wajcman J, Bijker WE (eds) The Handbook of Science and Technology Studies. Cambridge: MIT Press, 2008: 499-539.
- 30 Harrison S, Mort M. Which champions, which people? Public and user involvement in healthcare as a technology of legitimation. Social Policy and Administration, 1998; 32: 60-70.