Emerging versions of patient involvement with Patient Reported Outcomes

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Abstract. It is a central argument in the growing Danish PRO-arena, that a large-scale collection of PRO from patients in the Danish Healthcare system will pave the way for more genuine patient involvement in clinical decision-making, quality management and governance of the health services. In this paper I discuss how patient involvement is being (re)configured when increasingly connected to national visions of participatory healthcare. A central discussion centers on 'meaningful use' of patient-generated data promoting patients' expectations and experiences as a criterion for how to proceed with the national use of PRO. But how do assumptions of what constitutes meaning for patients interact with the kinds of roles that patients are expected to take on with PRO-tools? What forms of participation are assumed to be meaningful and thus good and which are not? In sketching emerging versions of patient involvement with PRO, I want to point to the need for further empirical exploration of how patients and professionals engage with PRO in specific daily practices and to stimulate a general discussion of all too simple normativities of the so-called 'participatory turn' in healthcare. I draw on empirical insights from an ongoing study of establishment of a national initiative for systematic collection of PROs in Denmark.

Introduction: The emergent Danish PRO-arena

"The patient is the new hype in the health services" a Danish newspaper heading (Information, 2016) professed with reference to the interview with leading

national expert on Patient Rated Outcome Measures (PRO/PROM) Professor Mogens Grønvold. Professor Grønvold argues that patient generated data from questionnaires are changing status among health professionals and policy makers from 'too subjective' accounts of individual experiences to reliable and timely data on patients' needs and outcome of clinical interventions (ibid). PROs are validated questionnaires collecting data on individual patients' own rating of their health and quality of life and the widespread interest in a systematic use of these tools in a Danish public health context is evident in the number of projects, agreements and institutional initiatives taken during the last few years: 159 PRO-projects were mapped as planned or taking place across the Danish regions (Danish Regions, May 2016), evaluation rapports published, public financing ensured in the national budget and new institutional frameworks established (eg. the office for PRO in the National Health Data Board Jan. 2017). Themes of patient involvement and participation are central to this accelerating development and Danish Patients (representing a all major patient associations) and the related Knowledge Center for User-involvement in the Healthcare sector, VIBIS, has had a central role in promoting increased use of PRO.

Analyzing Technologies of Participation

I see the spread of PROs as a reconfiguration of sociotechnical infrastructures of care that may have implications for what it means to be a patient and what constitutes care in practice (Langstrup 2013). As new tools, knowledge forms, organizational arrangements and accountability structures that are to be weaved into existing healthcare arrangements, PROs – together with other patient-involving technologies and initiatives – will have widespread implications for the daily lives of patients and health professionals. I draw on perspectives from Science and Technology Studies and in particular discussions of the interrelation between infrastructures, technologies and identities (Star 1999) and the politics and practices of care (Martin et al. 2015). The centrality of digital technologies in making patient and public participation in healthcare possible, calls for studies that explore how participation is discursively articulated and materially inscribed and "the normative variations among enactments of material participation" (Marres 2012: 2). Here I will sketch some of the emerging articulations of patient participation I have found in an ongoing study of PRO-tools that follows the national roll-out of PRO-tools. The empirical material consists of interviews with experts, policy-makers and other stakeholders engaged in the Danish PRO-arena (to date 8 interviews with 10 informants), participant observation at public meetings and conferences on PRO and written material. The preliminary insights give raise to a number of questions and concerns for research on participatory infrastructures of care.

Versions of patient involvement with PRO

By definition PROs demand the involvement of patients, in that patients are to answer a number of questions presented to them in the form of standardized and validated questionnaires. With these answers, it is expected, the health professionals and the healthcare system more broadly can better monitor the effects of treatment and ensure that interventions take into account what is important to and has positive effect for the patient. A more "needs-based" healthcare system. Still, it is stressed again and again by the proponents of these tools, that the use of PRO has to be implemented in a way that is valuable, relevant and meaningful for patients. In the report "Program PRO", where 26 experts made recommendations for the use of PRO tools on a national level in Denmark (VIBIS 2016), the concept of 'meaning' features 35 times in just 68 pages. Also in interviews with and meetings involving different stakeholders the concept of meaning features prominently. A high-ranking health official ends a public presentation on the national PRO initiative with a slide showing the face of an older man, with the heading "It has to make sense to Karl Anton!" and she urge the attending policy makers and clinicians to make this sentence their credo in the continued work with PRO. In the following I will sketch the ways in which patients are expected to be involved in and with PRO and how these versions of involvement relates to certain normative understandings of what are meaningful forms of participation.

Patient as data provider: A central activity for patients in relation to PRO is to provide data by answering questionnaires. PRO questionnaires may be provided in conjunction to a clinical encounter, to be completed in the waiting room, on paper or on a lab top. The patient may also receive the questionnaire at home via email, an online record or in paper form. Patients' role here is well known from the kinds of health-related quality of life research for which PRO-tools were originally developed. But the patient as being a 'mere' data-provider is problematized in relation to PRO. Proponents of PRO stress, that for PROs to be meaningful for patients, they need to be "active PROs", rather than passive ones. As a policy maker states, it is important "that you as a patient have the experience, that the answers that you have provided are used actively" (interview with policymaker, Sundhedsdatastyrelsen). "Passive PRO" in contrast would be data provided by patients and compiled for research or quality monitoring, but where the patient gets no individual feedback. Or "PRO for PRO's own sake" as a PRO-developer expresses it (interview). Passivity thus relates to the lack of response to the individual patient and is seen as problematic and something that might make PRO and the role as data provider meaningless for patients: "And then you have patients to answer and some clinicians who don't even bother to open [the PRO] on their screens. And it is exactly here, where they have been

sitting answering 'yes, I have sexual problems' and 'yes, I am sad' and then nobody sees it!" (Interview with PRO-developer). As PROs are framed as types of data that transport information to the clinic on what is important for the individual patient these data comes with a normative expectation of clinical action. The health professional must see and act on these data. But how is it experienced to be producer of data via questionnaires? Do patients distinguish between this and other instances in which they provide data? And how may health professionals in practice respond to these data?

Patient as data-user: The public visions of PRO position the patient as a partner with the clinician. The answers in the PROs are envisioned to be put to immediate clinical use in shared decision-making. Here the meaningfulness of answering PRO is achieved when the patient and the clinician in collaboration uses the data actively in the consultation – that it also makes sense to the clinician: "It has to make sense for both the clinician and the patient, otherwise nobody will answer or look at the data" (interview with policy-maker, Sundhedsdatastyrelsen). A researcher involved in promotion of PRO argues at a public event, that patients themselves talk about the data as "their data" and that it is the patient that uses the data to "involve the healthcare system in *their* life" – not the other way around. In the practical use of PROs the patient may also get direct feedback on entries and some suggest that these can be used for patient education or as part of self-care activities. PROs can be used to screen which patients in out-patient treatment have a need for a face-to-face consultation and who are well enough to be cancelled or given a phone consultation. This use of PRO is promoted as a more rational use of resources, as more convenient for patients and as a way to promote selfcare and empowerment. An algorithm generally automates the feedback the patient may receive upon their entries – i.e. a mail telling them, that they are doing well and do not need to see a doctor, or a visual representation such as a green indicator showing, that all is well. It is rarely transparent to the patient what in the questionnaire caused a particular response. Here PROs converge with other digital self-monitoring tools known from telemedicine. But will patients in practice experience themselves as active data-users when answering questionnaires or mainly direct their answers at the clinician, in the same way as giving a blood sample? Research on telemedicine has suggested that visions of empowering patients with technology are often inflated (Langstrup et al. 2013). And to the extent that patients do use data in the context of self-care and everyday life, in what – also unexpected – ways will they do so (Mol et al. 2010)? How will the specific configuration of digital care infrastructures with PRO enable "respons-able" care (Martin et al. 2015)?

Patient as co-creator of PRO: It is increasingly argued that for PRO tools to be truly participatory, patients need to be involved at every step in development and

use – as co-creators of the questionnaires, technologies and the interpretations of results (Staniszewska et al. 2012). In the context of the Danish development the Program PRO initiative was taken by a coalition of Danish patient associations putting patients institutionally at the center. Patient representatives are also in the clinical groups that are to select "national" questionnaires. Methodologically, in the construction and validation of PROs, patients are systematically involved. However, it is discussed if this is enough to qualify as "co-creation" (Ibid). The involvement of patients in the selection and validation of questionnaires may be said to have a "technocratic" or instrumental view of participation rather than a democratic aim if the primary goal is to increase answer rates (Martin 2008): "Patient need to contribute on what is relevant. Is this relevant to ask? If you don't feel that it is relevant, you wont bother answering. So if you want to have a high answer rate, it needs to make sense to patients" (interview with policymaker, Sundhedsdatastyrelsen). In practice intensifying patient involvement in design is not without challenges. VIBIS is one of the main sources of patient representatives and they increasingly have difficulties in supplying "good" patients for such "organizational patient involvement" (personal communication). Also, the balancing between patients' preferences, "the public good" and the wish among some experts to have standardized tools, which may allow for secondary use in research and quality monitoring, may prove difficult.

Discussion

In a Danish context PRO activities are increasingly framed as the road to genuine patient involvement in healthcare. Data provided directly from patients on their quality of life, functionality or symptoms is seen as a resource for more rational, patient-centered care and – potentially – value-based governance. The different versions of patient involvement articulated in relation to the promotion of PROs may in practice be deeply intertwined, but the analytical differentiation provided here may shed some light on normative assumptions involved. The concern for "meaningfulness" and the insistence that PROs need to be "active" point to an overall concern for the individual motivation of the patient. "Passive PRO" – PROs collected with no feedback to the individual patient – are articulated as problematic as the patient will not be motivated answering if the answers are not used for their own care. The version of participation that only gives the patient the role of data-provider is thus rendered practically and normatively problematic. Lack of individual motivation may cause low answer rates, disappointment as well as defying the purpose of letting the concern of the patient set the agenda in the clinical encounter. One researcher also compared passive PRO to data collected for research purpose among indigenous people in Greenland, who ended up protesting when researchers "left with their data". Patients 'own' their data and the health system should be 'respons-able' for taking these data into account.

It is thus also obvious that the meaningful use of PRO for the individual patient to a large degree depends on the moral obligations of the health professionals.

When it comes to the extent to which patients should 'co-create' the tools that transform their knowledge into data, the question of 'meaning' mainly seems to relate to the formulation and selection of questions, rather than the overall design and purpose of the tools. Also here there is a focus on the sensemaking of the individual patient, rather than negotiations of what might make sense for collectives of patients or society at large.

Rather than defining meaningful patient involvement with reference to conceptual framework and normative scales my interest here has been to explore, how such framings emerge as part of new sociotechnical infrastructures of care. The three emerging forms of patient involvement sketched here should thus not be seen as steps toward a more comprehensive and thus better form of patient involvement. Rather, each version may in different ways help us explore and question the implications of this widespread commitment to PRO as devices of participation. What happens with forms of patient knowledge, that cannot translate into (PRO)data (Pols 2014)? What if there are projects in healthcare that cannot be participatory or where participation comes as at a high cost for other valuable aims?

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