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Abstract

Patient-Reported Outcome (PRO) data are being widely mobilised as a means to implement clinical and governance decision-making systems based on measurement of "what matters to patients". Little is known, however, of *how* these—datified and calculative—versions of patients' embodied experiences become integrated in healthcare systems to achieve clinical, managerial and political goals. Drawing on data collected on a Danish national initiative to establish a questionnaire bank and a technical infrastructure for PRO data, this paper explores the epistemic and moral tensions of emerging infrastructures for patient-reported data. Our data reveals that those involved in crafting and developing the Danish PRO system seek to encode 'patient experience' in the Danish healthcare system by infrastructuring for the clinic, by infrastructuring for the organisation, and by infrastructuring for participation. The infrastructuring efforts in each of these domains involve tensions as the emerging phenomenon of PRO rubs up against existing

ways of working clinically and of enhancing and evaluating the quality of clinical care. Thus, while we share critical social science concern about standardisation of patient experience, we show here how those concerns are already pragmatically present in the infrastructuring efforts that patients, clinicians and administrators engage in.

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ORIGINAL ARTICLE

Infrastructuring experience: what matters in patient-reported outcome data measurement?

Henriette Langstrup[1] · **Tiago Moreira**[2]

Accepted: 27 December 2020

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Introduction

Patient-Reported Outcome (PRO) data are being widely mobilised in Western healthcare systems to ensure that clinical and governance decisions are based on measurement of "what matters to patients" (Coulter 2017). Sometimes also referred to as PROMs (Patient-Reported Outcome Measures), this is data concerning patients' own experiences of the effects of treatment, collected and encoded through standardised questionnaire tools generally administered to patients—at home or at the clinic—during the course of treatment.[1] The FDA defines PROMs as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" (US FDA 2006: p. 1). According to the NHS, "PROMs measure a patient's health status or health-related quality of life at a single point in time," (https://www.england.nhs.uk/statistics/statistical-work-areas/proms/).

PROs are seen to embody the goal of creating what Wachter (2015) labelled a 'learning health care system', where data are used to improve the organisation and delivery of health care. Thus, in the past decade, PRO programmes have attempted to link health care quality assessment to standardised experience data in countries such as the US, the UK or Sweden, in the past two decades (Black 2013; Nilsson et al. 2016). In this, PROs and the systems set up to collect them are promoted as *participatory technologies*, where data 'coming directly from the patient' are given a central place in healthcare decision-making—clinical or otherwise. In the clinical encounter, the promise is more personalised treatment, and, at a managerial level, more quality and efficiency. Thus, in 2017, the OECD issued a ministerial statement arguing for the need for better and more widespread use in member states' health systems of "measures of patients' own experiences of medical care and health care outcomes" (OECD 2017, p. 5). Such measures would, it was suggested, "better equip countries with data that reflect what matters to patients" (ibid, p. 15).

Taking as point of departure Hogle's call for research on how data is made meaningful and acted upon in interaction with "policies, technologies and social conditions" deploying novel infrastructures (Hogle 2016, p. 388), in this paper, we are concerned with the pragmatics of making 'patient's own experiences' usable for health care systems. The formalisation of 'patient experience', reconfiguring the subjective into objective, standardised data and useful data flows is no simple task (Shapin 2012). How is this done in practice? How and for what reasons are patients' experience of health services captured and measured? How does this data become integrated in existing health care organisations and systems? And with what effects when it comes to the role of 'the patient' and 'experience' in the healthcare system? While part of larger 'datafication' efforts within national health systems (Hogle 2016; Hoeyer et al. 2019), we find the mobilisation of PRO data particularly

1FL01 [1] In this paper, we mainly use the abbreviation PRO even if there are regional differences and some
1FL02 scholarly debates of terminology and delineation of PRO versus PROM. Some of these issues will be
1FL03 elaborated on in the analysis. Until then, the reader should see both abbreviations as referring to the same
1FL04 phenomenon.

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interesting because these efforts seemingly aim to align well-known expectations of increased efficiency and effectiveness with more democratising aims of "incorporation of the patient's point of view into the assessment of the appropriateness […] of professional allopathic medicine" (Sullivan 2003, 1995; also Moreira 2012). Through this process, patients are—through data on their subjective experience—enlisted as 'co-creators' of health services and medical innovation (Anderson & McCleary 2016).

However, turning personal experience into standardised data, which can be circulated and used for a multitude of purposes, is not without controversy. For example, Hausman (2015) has argued against aggregation and averaging of health states valuation because it makes equivalent conditions and situations, which are significantly different from an ethical point of view (life threatening vs minor conditions). Others have pointed to the tension between the rhetoric of personalisation in PROs and the reality that is brought to bear through aggregation of data (Prainsack 2017). This points to a further tension between the promise of personalization as a "deepening" of knowledge of the patient and the construction of standardised versions of experience devoid of real "patient knowledge" (Pols 2014). While we share a concern for "the seduction of quantification" (Merry 2016) resulting in instrumentalized versions of patients' voices, here, we are interested in investigating the pragmatics of these tools (Moreira 2018). In the paper, we focus, thus, on exploring the production of datafied, "thin" versions of patient experience through the negotiations and compromises involved in integrating it in existing, already data-rich health care systems.

Our approach to these questions highlights the complex and partial process of making a sociotechnical infrastructure for patient experiences. Using the notion of infrastructuring as a lens to analyse this process (Star and Bowker 2002), we focus on the relational, temporally emergent and performative dimensions of data and information systems (Karasti and Blomberg 2018). The concept helps us "theorize infrastructures as they develop" (Bowker et al. 2018, p. 212), making it possible to identify and map the multiplicities and uncertainties that are involved in the making of PRO. Using this approach, we suggest that the Danish initiative provides a unique window for us to investigate the formation of PROs in its 'preparation' or pre-launch phase, a critical period that shapes future development. In this, Denmark may be seen as a critical case for theory development (Yin 2017) of datification of health care, both due to the extent to which the relation between citizens and welfare institutions is already highly digitised and due to the country's long-term tradition for citizen involvement in policy and practice (Hoeyer 2016).

To do this, we draw on ethnographic and documentary data collected on the activities within a programme in the Danish Health System aimed at establishing a national questionnaire bank and technical infrastructure for PROs and tightly coupled with a more general national focus on health digitalization. Between 2015 and 2019, the first author participated in eight public meetings on PRO, conducted more than 40 h participant observation in a PRO project on heart rehabilitation and interviewed 15 stakeholders related to the national PRO initiative. The observations involved participation in workshops, some involving heart patients while others primarily clinicians in the area of heart disease and rehabilitation. Extensive fieldnotes were made during and after these workshops, complemented with documentation

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provided at the meetings. Informants for the interviews were selected through a snowballing approach to identify key actors in the Danish PRO arena. Semi-structured interviews were transcribed in full and anonymized. Online and print documents on the national PRO initiative and related activities were collected. We followed standard procedures of qualitative data analysis to build our model of domains of infrastructuring and their internal tensions.

In the following, we first offer a brief genealogy of PROs. Our aim in this is to explore the political and epistemic investments of such standardised measurements of 'patient experience'. This provides a useful background against which to understand the tensions experienced by promoters of PROs in Denmark. We then explore how they are reflexively addressed in the Danish case. Here we identify three domains of infrastructring—the clinic, the organisation and participatory arenas—each with its own set of tensions shaping what the inclusion of patient experiences as PRO data might entail in practice. We end by discussing the implications of our findings for how we may understand attempts to 'datafy' patient voices.

A brief genealogy of PROMs

As suggested above, the establishment of PROs as central tools in the international agenda for health care reform was sealed with the OECD recommendation in 2017. This drew on the work of the OECD High Level Reflection Group (HLRG) on Health Statistics, which argued that PROM programmes represented the best path for "countries [to become] well equipped to meet the challenges presented by ageing populations and the accompanying rise in chronic disease and multiple morbidities, [making] it essential that data collected are relevant and actionable, and correspond to what matters most to patients" (HLRGHS 2017, p. 15). In a commentary to the report co-authored by economist Michael Porter and OECD's Secretary-General Angel Gurría, it is argued that the change "requires asking patients themselves" their own assessment of health, quality of life in highly standardised way so as to make results comparable across time points, providers and across countries (Gurria and Porter 2017).

Porter himself is one of the founders of the International Consortium for Health Outcomes Measurement (ICHOM), an organisation dedicated to providing standardised sets of outcome measures, many of which are to be reported by patients (ICHOM 2018). In this vision of "putting people at the centre", patients are granted a central role in healthcare management: by providing information about their health, patients not only inform decisions regarding their own treatment, but also provide the means for governing healthcare on their behalf. This can be seen as the realisation of Michael Porter's highly influential work on Value Based Health Care, where value is defined as "the patient health outcomes achieved per dollar spent." (Porter 2010, p. 2477).

The linking of more efficient health care to standardised measurement of health is not new. Indeed, it has been a consistent orientation in attempts to reform health care for at least 40 years (Moreira 2012). Nowhere is this linkage more clear than in the proposals attached to US health reforms in the 1980s. One of its key proponents,

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Paul Elwood argued that the transition from a centralised administration of health care to a distributed, networked structure would have to rely on a shared information infrastructure focussed on outcomes. Outcomes management, he argued, would provide the infrastructure for "rational decision-making" in health care, orienting insurers, providers and users towards common goals (Elwood 1988). In this, he argued that *experience* played a key role:

> The intricate machinery of our health care system can no longer grasp the threads of experience. […] our common interest is the patient but we represent that interest from such divergent even conflicting viewpoints [that we now] need a central nervous system. […] I propose that we adopt a technology of collaborative action […] Outcomes management is a **technology of patient experience** designed to help patients, payers and provider make rational choices. (Elwood 1988, pp. 1550–1551; our emphasis).

Specialisation, the different perspectives and interests of healthcare actors, and patients' lack of information on quality to inform their choices on a health market thus called for a 'central nervous system' based on "measurements of the effects of choices of patients, payers, and physicians on the patient's aspirations for a better quality of life" (ibid). Such measures should become "a new universal language of hurting, functioning, working, interacting, and living" (ibid: 1551).

That language, however, according to health care reformers such as Elwood, was not to be found on doctor's assessments, insurers' valuations or patients' individual opinion. Rankings and preferences aimed to establish a 'universal language' through rendering equivalent and comparable the effects of health care across contexts, conditions, specialities, organisations and patients. What was required was a form of measuring outcomes based on an objective assessment of 'patient experience', an operation that would encode a stable qualification of wellbeing and function across individuals and context. Developing and using a measure of health would be what Thevenot (1984) described as an "investment in form", embedding a stable form of qualification of objects or persons, facilitating its quantification, and enforcing a specific mode of political coordination that enacts efficiency.

Interestingly, Elwood suggested that the exemplar route for this future 'technology of patient experience' was the Medical Outcomes Study's (MOS) search for "practical instruments for measuring outcomes" (Elwood 1988, p. 1552). Aiming to develop a measurement of health to quantify the effects of different health approaches within the RAND' Health Insurance Experiment, MOS investigators drew on the WHO 1948 definition of health to propose a model that "take(s) into account the cognitive processes underlying the *evaluation*" that participants made about the functional, mental and social aspects of their health, (Ware et al 1980, p. 12; our emphasis). Enacting this evaluation as a 'cognitive process' was pivotal because it made health amenable to be investigated through psychometric methods. Thus, it became one of the key aims of the health status measurement team at the MOS to systematically perform "psychometric evaluations" of the ratings used in health questionnaires. From this work, it would eventually emerge one of the most commonly used health outcomes measurement instruments – the 36-Item Short-Form Health Survey (Ware and Sherbourne 1992)—which remains a point of

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reference for those proposing the implementation of PRO data collection and analysis in health systems, such as the OECD HLRG on Health Statistics (see above).

From a science studies point of view, psychometrics is one of most established techniques through which psychology enacts its object of inquiry (Igo 2007; Young 2017). By enabling the mapping of personal qualities in mathematical, structured measurement, psychometrics facilitate the generation of inscriptions—distribution curves, etc.—that can be compared, correlated, subsumed and integrated (Latour and Woolgar 1986). The transformative capacity of psychometric procedures is thus epitomised in the reconfiguration of a fuzzy, deeply subjective thing such as 'experience' into a tractable object enacted as a psychological operation of 'valuation' of information.

This brief genealogical exploration, enables us to understand how PROs are layered on a complex sociotechnical assemblage that configures experience through the application of psychometric techniques, eliciting subjectively experienced phenomena and converting them into objective, quantifiable data. This is explicitly justified as a means to ascribe value to health care interventions or programmes that are seen as competing for a limited pool of resources. As we will see in the analysis below, however, deciding what matters in infrastructuring experience with PROs is not a simple implementation process, and is instead laced with uncertainty.

The Danish Case: Infrastructuring experience in a data-intensive healthcare system

Denmark is a critical case study to understand the dynamics of infrastructuring experience. As a nation undergoing an overall transformation of infrastructure defined by Hoeyer (2016) as "intensified datasourcing", Denmark has recently made comprehensive investments towards using extensive patient-reported data across the health care system (Ministry of Health 2018, p. 27). As a result, Denmark has a highly developed digital health infrastructure with patients generally said to have trust in health authorities also accustomed to have their health data shared digitally among various health providers. Nevertheless, recent intensification of data sourcing have sparked public controversy (Wadmann and Høeyer 2018) and revealed the many, partially contradictory aims and stakes involved (Høeyer 2016). In this, it has become apparent that neither public nor local legitimacy of new data sourcing practices can be taken for granted.

This is also the case with Denmark's national PRO infrastructure, brought to bear by two different, partly overlapping initiatives: a Value Based Healthcare initiative led by regional authorities (Danske Regioner 2015; Pedersen 2017), and an initiative promoting PRO data as means of patient empowerment and clinical quality—Program PRO. In the first of these, inspired by Porter and experiences in other countries, Regional authorities set out to test if principles from VBH approach could provide alternative, less activity-focussed and more patient-centred forms of healthcare governance. In this, PROs featured as central tools to enable change. According to an analysis of the initiative made by Bonde et al. (2018) the concept of VBH was locally translated by connecting with "existing practices, agendas and

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commitments" (Ibid: p. 1119). Patient experience was not, as intended, stitched into the attempts to build an alternative governance infrastructure (KORA 2016). Nevertheless, funding was secured for supporting widespread, cross-sectorial use of PROs (Finansministeriet 2016, p. 33).

The second of these was instigated by a broad coalition of healthcare actors, aiming at building an expansive, continuous and cross-sectional collection of patient-reported data. The plan was an offshoot from a project—Program PRO—initiated by a large patient association—Danish Patients—involving 29 experts across different fields and institutions, who, in a 2016 report, had provided recommendations for the use of what was termed "PRO data" throughout the Danish health sector (VIBIS 2016). The definition used in this report was more closely related to the FDA definition mentioned above than that used in the VHB approach, with a focus on data reported directly from the patients on their experience of their state of health. Thus, the aim of using PRO data is seen to be justified at both the individual level, for the clinical dialogue and "involvement" in decision-making, and at an aggregate level, for research, clinical databases and as a quality indicator/metric. Throughout the report the main emphasis, however, is on making the patient "a partner" in the Danish health care system so that decisions both at the clinical and the managerial level should be based on "the perspective of the patient", tying this data intensification practice to the rhetoric of patient empowerment (Armstrong 2014). Interestingly, the report contains only one reference to Porter and his concept of VBH Value Based Healthcare is not mentioned at all.

The report was greeted with enthusiasm by policy makers, and a National PRO office was established in 2017 under the auspices of the Ministry of Health, drawing on a cross-sectorial steering group (Langstrup 2018). Since then, the National PRO office has had as its primary task to support the widespread use of PRO data, by selecting and/or developing the specific questionnaires to be put in a national PRO bank, and setting the national standard for relevant "crown-marked" PRO tools in a number of clinical, cross-sectional treatment areas (pro-danmark.dk). Central to its task is also to make the national IT-infrastructure suitable for sharing PRO tools and PRO data across sectors. The work is meant to be highly collaborative, with questionnaires selected and/or developed with the involvement of patients, health professionals, patient associations and those responsible for existing quality databases collaborating in "clinical coordination groups"(CCGs).

As of August 2019, six CCGs were completed. The groups were organised two interlinked sub-sets: one primarily for clinicians with a patient representative, and another specifically planned for patients. This arrangement was intended to underline the important role of patients and patient empowerment in the PRO programme. Plus, the clinicians involved in the subgroup should represent all relevant clinical contacts that a patient in the specific treatment pathway might have. The clinicians were appointed by their local region, municipality or professional association. The goal of the meetings was to develop a description of a cross-sectorial patient pathway, to identify points at which patients should be asked to provide PRO data, agree on the purpose for which the data were being collected in the clinical context, and decide the specific questionnaire tools and items that should be used at each data collection collection. In the end, the 'package' was to be piloted in clinical practice,

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and then made available in local record systems via the national IT-infrastructure. At the end of the fieldwork period (September 2019), five of the six groups were at the piloting stage of implementation.

In the next section, we will focus our analysis on the Program PRO and the work CCGs. Departing from the knowledge that the programme was explicitly set up to distinguish itself from VBH-projects, both in Denmark and internationally, we explore how by aiming to link PROs to clinical practice, organisational aims and patient involvement, the initiative provides a unique window into the tensions that are inherent to personalisation-through-standardisation which lay at the core of visions of data-driven health systems. It is to these tension that we now turn.

Infrastructuring for clinical work: Making PRO clinically meaningful?

In designing Program PRO, its leaders were mindful of the political connotations associated with standardised outcome metrics, and in particular its connection to Porter's market driven vision for health care. In order mark Program PRO apart from the VBS initiative and international initiatives using PROMs, its leaders agreed to exclude the M for measurement in the definition of the standards the programme was aiming to establish. As one of the experts involved in the initial report and the national initiative suggested, they chose to take out the M because they did not want to indicate a close relation to the use of these tools as part of population-based managerial targets, the primary application of PROMs in the US and UK (Interview and fieldnotes). They were concerned that, for example, in the UK, challenges had been pervasive in motivating patient and clinicians to collect the data as it was only used at an aggregated level for management, with resulting low reply rates. Seeing this as indicative lack of ownership of the process among clinicians in particular, it revealed problems of legitimacy of PROMs programmes. Moreover, concerns of PROM data being associated with increased 'paper' work, taking up clinicians time—something that had been publically debated over a number of years—made the enrolment of clinicians a particularly pertinent issue (Langstrup 2019, p. 572). Consequently, the leads in the Danish PRO programme were focussed on establishing a close, positive association between PRO and clinical practice. As one health services experts put it in one of our interviews, "PRO needs to be generated in the clinical meeting between the health professional and the patient. That makes it meaningful for the patient and for the health professional" (Interview health services expert 2017).

The insistence on "clinical meaningfulness" translated into a much used further differentiation in the Danish arena between "active PRO" and "passive PRO". In this distinction, the first is seen as the preferred form of practice in which data are collected for immediate use in the clinical encounter, with possible secondary use for quality monitoring and research. By contrast, "passive PRO" is equated with the collection of the same data, but with no immediate clinical relevance or action taken as a result. Thus, in the "Values" section of Program PRO, it is stated that "PRO data should support relevant dialogue between patient and health professional" and "be meaningful for patients, health professionals and management", while also

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contributing "to improve the outcome of patient pathways and thereby contribute to visible value for the patient" (VIBIS 2016, p. 38).

"Clinical meaningfulness" and "active PRO" can thus be seen as a strategy of enrolling clinicians as central actors in the infrastructuring of experience. This objective also justifies the composition of the CCGs, mainly consisting of physicians and nurses from the relevant clinical areas. In the CCG workshops—often more than 4 whole day meetings spanning over 6 months—it was continuously stressed that the goal primarily was to facilitate the use of PRO data in a clinically relevant way—to inform clinical dialogue, screening based on patient needs or clinical decision-making—and only secondarily for quality management or research. For instance, a PowerPoint slide shown at several of the CCG workshops on heart rehabilitation, under the heading "Why is PRO a good idea?", pictured a person, presumably the patient, with different light sources illuminating the figure: "the record", "test results", "the consultation" and finally "PRO data". On the same slide, different "perspectives" on PROs relevance were listed, with benefits for "the patient" and "health professional" at the top, and for "process" and "development" below and in semi-transparent colours, clearly signifying that the latter benefits were secondary.

One difficulty that arises from this emphasis on clinical relevance, however, and in differentiating the PRO initiative from other data-driven efficiency efforts, is that the measures or data at the centre of the groups' deliberations are standardised measures such as SF-36, used in extensively in both VHB and PROMs programmes. Many clinicians involved in the groups we observed knew the English terms of such tools from using them in clinical research or from working with clinical quality databases. This made the terminological monitoring of the use of "active PROs" extremely challenging when promoting the national initiative to clinicians at public meetings and when working in the CCGs, as we illustrate below. Moreover, several of the participants in the CCGs were also already engaged in the national VBH-projects where the concept of PROMs was used early on, and where the primary target was value as understood in economic terms.

In the CCG on heart rehabilitation, for example, this tension between played out at several occasions through the argument put forward by some clinicians that "passive PROs" could be equally meaningful for clinical work. In this, a key discussion concerned whether or not it was meaningful to ask patients to fill out a PRO questionnaires to serve as "baseline data", even if it would not inform any immediate clinical action. Would it be appropriate, theyr asked to ask for type of data, for instance just before patient's heart surgery? The clinical meaningfulness of this data input was not clear, or as one consultant phrased it, "It is important that we don't invent *data collection consultations* with no clinical purpose!" (Cardiologist heading the CCG, fieldnotes). Some of the clinicians further argued that the stress induced by the questionnaire filling would be an undue burden for patients: *"When discussing whether sexual issues could be part of a baseline questionnaire, one clinician bursts out "But isn't that totally irrelevant when you are in shock after your ticker just stopped?! Should I then have to consider if I have a satisfying sex life? I have just written my testament!" (Fieldnotes).*

For this clinician, as for others in the group, PRO data tools should not add complications to situation that are by their nature already taxing for the patient and

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clinician. This assessment was challenged by the view, usually voiced by clinicians engaged in VBH or clinical registries, that such baseline data would enable measurement of aggregated outcomes of interventions, and thus to evaluate the effectiveness of treatment provided: "Now it [the outcome of treatment] is a black box! We want to know if they are getting better!" (Cardiologist engaged in VBH initiatives, fieldnotes).

The tension between the personalised care vs the standardised measurement was nowhere more visible that in relation to issues of validity. When choosing questionnaires in the CCGs, there was often a choice between disease-specific or generic tools, such as the SF-36. To aid with this process, the PRO office is responsible for providing participants in the CCGs with an overview of possible tools and a literature review covering evidence of their use and validity. Participating clinicians may have had experience of working with some of these tools, or routinely use one or more of the tools in their clinical practice, as mentioned above. Among the involved actors, there a general trust in the ability of questionnaires to collect important data on patients' experiences of their own health to support clinical care. However, this trust has been criticised as methodologically naïve, with some experts voicing concern about the procedures used by CCGs to select PRO tools, and the epistemological assumptions of the whole national PRO initiative (Interviews with questionnaire experts).

For example, in the CCG on early detection of depression, clinical psychologists openly questioned the way particular questionnaire tools were selected for the national PRO bank (interview with participants). These participants had previously been involved in the National Health Authorities development of evidence-based clinical guidelines for early detection of depression. They argued that the relevant clinical guidelines had not been taken adequately into account at the CCG workshops (interview with participant). While the guidelines recognised a diversity of trajectories onto depression, the CCG had proposed that the same generic PRO-tool could be used to screen for such different trajectories. This was highly problematic: "We were just told, it has to be generic. Where did that come from? What is the argument for that?"(Interview with psychologists). Referring to existing evidence on screening for depression within particular somatic areas, they suggested that the correct way would be to use the screening tools validated nationally for the specific disease area, or at least for those to be taken as a starting point, rather than trying to find a generic tool. As one of them put it to us later, "the quality of the new [tool set] they wanted to deliver was worse than what was already there—in terms of its validity…" (Interview with psychologists).

The experience methodological experts was that the production of comparable data was prioritised in detriment of using the most adequate tool for the clinical situation. Indeed, a consistent critique raised by researchers with expertise in measurement, statistics and quality of life hinged on how the questionnaire tools to be used in the within the national PRO initiative had originally been developed and validated for significantly different purposes (Interview with questionnaire expert). Many PRO tools were initially developed and validated for application in research at a population level but now the same tools would be used at the level of the individual for clinical purposes. This critique goes to the heart of Program PRO's aim

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to make measures 'clinical meaningful'. How can they be meaningful if they are not valid? And what counts as validity in a clinical and personalised context? Such issues remained unsettled in the negotiations to infrastructure patient experience.

This critique also pertains to the proliferation of PRO tools being developed ad hoc, and to the editing of existing validated tools for clinical purposes or to encompass requests from patient representatives. Little is known about the effects of these changes on the validity—not to speak of sensitivity and specificity—of the tools, and thus on clinical decisions and outcomes. Again, how important this lack of information is depends on their pragmatic enactment, i.e. whether the tools are to be used mainly to raise awareness of issues to address in a person-centred, personalised dialogue, or to become embedded in an evidence-based algorithm to support prioritisation or future decision-making. If the latter, importantly, using unvalidated tools would render results incomparable and hence problematic to use at an aggregate level—whether for clinical decision-making, research or quality management.

It is important to note that national initiative's explicit orientation is that only validated tools should be included in the PRO bank. However, as the example above shows there isn't necessarily agreement across participants on what constitutes rigorous measurement, or what validation is for. In an interview with a manager in the national PRO office, she suggested that it is necessary to be 'inclusive', being flexible on the criteria use to evaluate tools already established within specific clinical practices. These, she suggested, might not have be rigorously validated scientifically, but only "tested": "What if they [clinicians, ed.] in North Region have been using a questionnaire for a hundred years and have tested it and everything. Then what?!" (Interview, PRO office 2017).

The key to the interviewee's reasoning lies in the differentiation between validation and test. In her view, the questionnaires and algorithms used by clinicians are "tested", but not necessarily to the high standards of formal, methodological questionnaire validation. The test, then, is here a pragmatic form of validation, provided by the habitual use of a tool over a number of years ("a hundred year"), rather than by experimental procedure (Marres and Stark 2020). A recognition of the relational and potentially unsettling character of PRO infrastructure, the preference for continuity of use of 'tried and tested' tools denotes also an attempt to align the PRO programme with existing clinical practices. It is from this perspective that we can understand another interviewee's observation that the national PRO approach is following an "implementation logic", rather than a scientific logic, wanting to ensure speedy diffusion of PRO tools rather than a sound basis of evidence: "For them [proponents of the national initiative, ed.] a questionnaire is a questionnaire and we just have to get started and push ahead" (Interview with questionnaire expert).

The pragmatic focus on implementation is buttressed by the optimist agenda surrounding the use of 'big data' in health and healthcare (Prainsack 2015). In this, technological promises associated with generating new kinds of data blur established boundaries between reliable, valid and invalid data. This is not to say that the protagonists are indifferent to the kinds of data collected. Rather, they explicitly address this issue as requiring balance or compromise. As a physician and health services professor put in at an international seminar organised by the National PRO office, "this is about data and standardisation, but it also about dialogue and everyday life"

(Fieldnotes). Balancing methodological concerns with a focus on ensuring meaningfulness for clinicians is a key requirement of the PRO infrastructure. Tools chosen with reference only to scientific rigour, but without adequate involvement of the stakeholders might hamper the implementation the national PRO bank in and across practices, and thus decrease the reach of data-driven health services.

Infrastructuring for the organisation—balancing efficiency, actionability and control

In the previous section, when analysing the work of making PRO data clinical meaningful, we touched upon the relational character of infrastructure, and in particular on how it relates to "the installed base" (Star and Ruhleder 1999, p. 382) of clinical work already entangled with research and governance practices, and measures of patients' experiences. While the focus of much of the PRO initiative lays on its clinical use, downplaying its economic efficiency aims, better prioritisation, planning and cross-sectorial coordination remains unsurprisingly a central aim of the initiative. Making patient flows across the organisation "data driven" rather than "calendar driven" is a key flagship aim of the national PRO initiative, and seen as a necessary step to avoid waste of resources in a context of increasing demand from raising numbers of chronic patients. Monitoring patients with PRO data will enable, it is argued, the use of algorithms to calculate and plan appointments, in a needs-based and efficient manner.

In this, it is significant that protagonists draw on the example of "telePRO", a system already in use in a number of different specialised treatment pathways such as epilepsy, asthma, diabetes, where patient regularly log PRO questionnaires. In this system, data are then processed by an algorithm to determine thresholds for 'clinical action', such as the automated cancelling of an appointment or the triggering of a phone call by a nurse checking on the patient. The system is well aligned with policy calls for using digital tools and data to curb increasing demands, the Danish Ministry of Health arguing that "there is really no alternative to increased digital collaboration" to ensure a "sustainable development of our healthcare system" (Ministry of Health 2018, pp.8–9).

Within such a political landscape, CCGs are mindful of the risk associated with using efficiency as a chief policy aim for PROS. In this, they often argue that the Ministry of Health is not promoting PROs simply as a way to cut services, but rather to as a means to "prioritize" and "set resources free", focussing on the possibility of putting infrastructure to make data-driven choices. However, using PRO data for a more efficient and data-driven organisation rubs up against other organisational and professional concerns. While there is very little opposition, on a general level, to the idea of using PRO data on issues such as QoL or mental distress, clinicians raise reservations about the actionability of the data that will be obtained through these means. The question is that PRO data might also generate and make visible extraneous needs and concerns: "Sleep! But what the hell am I to do about that with my cardiology expertise? […] We should not ask about things that we just leave

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unattended, [because] then patients will be very disappointed" (Cardiologist in clinical coordination group, Fieldnotes).

How, the clinicians ask, should they deal with the possibility of new demands for managing issues that they neither have the expertise to address themselves nor (knowledge of) services to refer the patient to? Several times such questions were raised as professional—and ethical—challenges for clinicians not used to dealing with issues ranging from sleep, as in the quote above, to sexual health or loneliness. These problems also pertain the organisational aims of using PRO data as a means for more efficient care. How can resources follow the data when clinicians do not feel empowered or capable to make decisions on areas beyond their expertise.

Our fieldwork suggest that the solution to this tension was seen to be in a re-articulation of the role of clinicians. The head of one of the CCGs we observed expressed this pragmatic compromise at a meeting thus: "When some chief physician says to me, "I don't want to ask about loneliness, because I can't do anything about it!", I tell him, that the patient wants to be asked anyway. They want a referral. You will just have to refer the patient to a specialist" (fieldnotes).

So the argument is that clinicians are not to handle these issues, rather they are just expected to help the patient navigate the process toward the places and people that can help them—be it elsewhere in the health system or in voluntary and patient organisation. Actively guiding the patient through the health system is justified not only by its individual benefit but also by how it might reveal priorities to be pursued. From this perspective, making visible hitherto unrecognised needs is a marker success of PRO data. As one clinician put it in a CCG meeting, "If it is what is important to our patients, then that is what we should develop our health system toward" (fieldnotes).

The organisational aim of the national PRO initiative is thus that PRO data should be used for coordinating patient trajectories, by directing focus on needs and outcome of treatment. In this, health care professionals are to be enrolled as organisational experts, translating data into shaping patient's pathways in the health care system. This, however, is not a simple task. Patient pathways are complex organisational infrastructure (Allen 2014) into which PRO data are to be weaved. It is recognised that the embedding data in pathways requires 'data work' from clinical practitioners. Therefore, actors across all relevant sectors involved in the particular treatment area are purposely invited to participate in the CCG, in order to identify opportunities for embedding data in pathways. As a result, at CCG workshops, a lot of work goes into articulating—for instance, through drawing exercises—what might constitute a common patient pathway along which PRO data can be produced and used, notwithstanding the variability of locally ways of organising activities. In this, pathways are reconfigured as occasion for collecting and deploying data.

However, the challenges related to mobilising all relevant actors and sectors along specific treatment trajectories are not trivial. Who should be included? More importantly, who can be included? In the CCG on heart rehabilitation, for example, the group comprised heart surgeons, heart nurses, physiotherapists, nutritionists, psychologists, patients and representatives from the patient association, but did not include general practitioners. This is because the General Practitioners Association (DSAM) has generally been averse to appoint their own representatives. As a result,

only two of the six CCGs include a GP representative. Their dislike of the PRO programme has roots in earlier controversies about their professional autonomy, and role as the patients' privacy guard in an increasingly data-intensive health care system (Wadman and Høyer 2018).

While acknowledging that PRO data might have some potential for ensuring a patient-centred health system, the GP Association, in its policy paper on the issue, stressed that there was lack of evidence on the effectiveness of PRO to bring about such system (DSAM 2017). This is compounded by a significant burden of data work on patients and clinicians, with the risk of diverging their attention away from clinical relevant information toward irrelevant data "polluting" the record and the consultation (ibid). For the DSAM, PRO data are a challenge to the central role of GPs in health care systems such as the Danish, where their work as the systems' gate keepers is supported by a pragmatic focus on the 'whole person', Patient records and AQ4 data should be curated to support this configuration of GP and patient's identity. In this regard, GPs role in data collection, curation and processing is not solely contributing to the infrastructure, but should be seen as "a filter, which minimises the risk, that the overview of the record is hampered by excessive or unwanted PRO data" (DSAM 2017: PP). Instead, Danish GPs appear to be saying, CCGs aim to plan the 'overview' from above, by committee, away from the clinical situation, imposing roles and identities to actors in the health system.

It is not surprising that the absence of GP representatives in CCGs is a matter of some frustration within the groups, as they are recognised as a key component of health care system and in managing patient pathways. Participating patients, in particular, are bewildered by their nonattendance, which they see as undermining the potential PRO data has to transform patient care: "In the patient's diagram of their shared experience of an illness trajectory, the GP figures twice—at the beginning and at the end of the trajectory. When reviewing the illustration at the second workshop, one patient says 'It doesn't make sense that the GPs isn't here (in the CCG, ed.) when they are in the drawing!'" (fieldnote).

For the promise of PRO to be brought to bear, patients in the CCG were suggesting, it is necessary that all actors are aligned through the standard patient pathway. Misalignment, or lack of buy-in, from a strategic group of actors opens up the uncertainties inherent to implementing a new data infrastructure. This is a crucial element of the process of infrastructuring. As the temporally emergent character of PRO data becomes publicly visible, as the sociotechnical promise it embeds reveals its partiality, the value it aimed to brings forth is threatened and diluted, and its costs emphasised.

This issue is further exemplified by the enhanced visibility of possible tensions between the new data infrastructure being proposed and the 'installed base' of different patient record systems used in different regions and different sectors, already mentioned in the previous section. Decisions on which record systems to use have long been delegated to regional authorities, municipalities and general practitioners. Although a number of inter-operability solutions have been put into place, there are still challenges and uncertainties on how to calibrate the different structures. As a recent, problem ridden, attempt to implement an electronic patient record and management system across two regional authorities—Sundhedsplatformen—makes

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clear, the aim to homogenise the types and amounts of data that should be included in patient records, across regions, goes against the practice of autonomy within a pluralistic, devolved administration. Indeed, even within the PRO programme, regional authorities have insisted on being free to choose the supplier of the specific PRO module tasked with distributing questionnaires, collecting answers, calculating and displaying results.

CCGs are acutely aware of this issue. The heart rehabilitation CCG, in particular, has voiced its concerns to the national PRO office, asking if the technical, inter-operability infrastructure would be in place. The answers suggested optimism at best but also expose the limited control national data authorities have to impose new standards. Enacting a 'digitally led', patient-centred, efficient health care system taunts existing health data infrastructures and their embeddedness in political structures. As the tensions between 'old' and 'new' ways of organising health care become visible, the neutral character of PRO data infrastructure is opened to questioning and critique. While leaders of the programmes have put much emphasis on distancing PRO programme from the economicist, politicised vision apparent in VBH, CCGs' work of assembling PRO data architecture requires a re-distribution of power, asking some health care practitioners to take on new duties and identities, and others such as GPs to forego existing ones. In doing so, PRO data destabilish not only the professional order of the health care system but also its administrative procedures, institutions and power structures. Paradoxically, while it claims to make health care more responsive to patients' needs, it does so by denting professionals' capacity to curate data and adjust data architectures to local authorities and local practices. Circling this conundrum requires publicly evidencing investment in making data tools directly linked to patient participation and involvement.

Infrastructuring for participation—how to make PRO data matter to patients

A final domain of pragmatics of infrastructuring patient experience through PRO data concerns the ways in which the mobilisation of these measures involves enrolment of actual patients in CCGs. This is the key means through which CCG aims to ensure that PRO infrastructure enables patient participation in data collection and use. In this respect, once again, Program PRO positions itself as an ambitious programme, aiming to bring together two forms of participation. On the one hand, PRO data are seen to enable individual participation in health care, supporting 'clinically meaningful' and personalised care. However, qualitative research of patients' experiences of PRO/PROM supports the argument that the collection of PRO data in itself should not be seen as participatory, only becoming so when used to facilitate dialogue or learning (Boyce et al. 2014; Mejdahl et al. 2016). Others, taking a more political stance, have argued that PROs can only count as genuinely participatory if the measures themselves have been developed through meaningful involvement of patients in their construction (Kirwan et al. 2011). This latter position is more focussed on what could be labelled "collective participation" as a form of democratic representation.

The aim to bring together these two forms of participation appears to have been reinforced by the extraordinary engagement of patient associations in the initial mobilisation of PRO in Denmark. The national PRO initiative has involved patients and patient associations in the process of choosing PRO tools for the national PRO bank. This was done in two ways: by including patients and/or their representatives in CCGs, and by organising parallel patient workshops which feed their deliberations to CCGs. The key challenge faced in the parallel workshops, in particular, was finding the adequate frame to make sense of the process: what were these forums for? Should they be organised as consultative meetings, where patients are asked for their views and preferences, or should they have deliberative capacities? What might be the right tools and formats for teasing out what true and relevant patient experience is?

Rather than a simple policy decision, this required crafting and qualification of the interaction between group members. The meeting followed a set structure. First, staff and consultants from the PRO office would introduce the concept of PRO. Second, patients discussed and mapped their experiences onto disease pathway across sectorial borders. These maps and diagrams would then be linked to specific PRO areas and measures chosen by clinicians. A discussion usually followed about their usability and relative importance. The main conclusions of the workshops would subsequently be communicated to the CCG, who would make the final decisions on which PRO tools to choose. This procedure, however, raised the risk of patient involvement being deployed as mere consultation. To mitigate this risk, CCG chairs were committed to amplifying the role of patient input in CCGs. As the chairperson of the CCG on heath rehabilitation put it: "We may think that we already know what [questionnaires, ed.] to use. But that is not how it is going to be here. We cannot take the tools right off the shelf. We need to start from scratch" (fieldnotes).

The differentiation between 'how it's going to be here' and a situation where PRO tools are 'taken off the shelves' is intended to mark an epistemic and political boundary. The knowledge process that supports the choice of PRO tools is robust, according the chairperson, insofar as patients' contributory role is recognised. This means that it should be possible to explicitly trace how the views expressed by patients shaped the outcome of the CCGs. One condition for enabling patient's contributory role was for patient to be adequately equipped. For this purpose, all patients involved in the workshops had to be 'educated' on the purposes of PRO data, and on the variety of questionnaire tools through which the data could be obtained. Patient saw their role mainly as providing a 'reality check' on the usefulness of the tool, based on their experience. During fieldwork in the workshops, patients consistently found all the possible PRO areas suggested to them (physical functioning, social functioning, quality of life, coping, pain, self-management, diet, sleep) as relevant, and related many of the themes to experiences they had had as part of living with a heart disease: "Sitting while reviewing the questionnaire themes presented, a spouse whispers to her husband, a heart patient: 'I think all of this is relevant, don't you think?'. He responds in low voice: 'Yes'. The patient next to them agrees and continues, 'but we don't have to deselect anything'" (fieldnotes).

Not seeing themselves as responsible for selecting one tool over another should not be interpreted as an accountability shelter, as patients also clearly suggested that

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they were not interested in answering questions if their answers were not addressed and acted on by a clinician. As noted in the fieldnotes, "everytime the patients discuss a questionnaire theme they talk about how the answer will help them talk to the clinician about important issues" (Fieldnotes). While this position was aligned with the "active PRO" vision, it also fuelled clinicians concerns about guaranteeing actionability of data, as discussed above. Taking patients' views seriously would mean committing to this pledge, so as to ensure individual and collective participation. Rather than providing a new start on how and why tools should be chosen, patient involvement resulted primarily in heightening the political stakes of the initiative. But making such politics visible threatens the stability of the consensus that deliberative processes are supposed to bring forth.

Where patient where willing to provide views on the tools themselves, their main concern was that PRO questions were difficult to understand or phrased in an outdated way. For instance, in the heart rehabilitation CCG, patients expressed a negative opinion of the format and content of PHQ9—a questionnaire for screening for depression—which the chairperson half-jokingly said annoyed her because of how it focussed on a narrow range of behaviours. However, as she put it herself, "unfortunately it is one of those that we would really like to use for research because of its high internal consistency in statistical terms" (fieldnotes). So here, including patients also implies to trade-off scientific rigour, and introduce potential challenges of measurement inertia, if measures are already organisationally embedded in clinical or research practices. The work of ensuring participation then requires persuading patient representatives that the narrowness and intrusiveness of the questions can be justified by the reliability and sensitivity of the tool.

While there has been and continues to be an extraordinary support for the introduction of PRO data among patient associations, tensions are also experienced in this domain. This pertains not only to the actionability of the data or its relevance, but also the ability of data to make durable connections to the whole population of patients and its wide range of everyday life concerns, or to put it another way, to the representativeness of patient reps. Both patient representatives and clinicians in the CCG on heart rehabilitation were very concerned about this issue involved: "One of the clinicians asks: "How were they selected? It is always the active patients who participate in things like this". The head of the CCG says, that they come from all walks of life" (fieldnotes).

Both clinicians and patients themselves questioned if patient reps could reasonably be seen as legitimate spokespersons for all heart patients. IN this they were concerned that their orientation toward 'active PRO' might exclude passive, "weak patients" and their abilities to engage meaningfully with PRO. In particular, clinicians expressed concern that some patients might experience PRO as yet another burden of treatment, and as a form of paternalistic or moralising surveillance. One nurse called for increased reflection among the clinicians about this problem: "Have we really considered what it is that we are doing, asking all these questions? Maybe the patient just wants to get home and drink a lot of beer? Should we dictate what constitute quality of life for the individual? No we shouldn't! We should not be moralising".

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Aiming for a widespread, systematised, standardised and continuous form of participation needs individual patients for whom answering questionnaires is seen as meaningful, and it needs patient representatives to provide input and legitimacy to the very process of infrastructuring for experience. But again, the onto-normativity of questionnaires is brought to view in the process developing the PRO database. What and why should we be asking about? What justifies changing our practices of data collection? While publicly making the case for PRO data to enable a form of 'grass-roots', bottom-up health care politics, the CCGs repeatedly confronted the fact that selecting standardised tools would deploy top-down, expert-led setting of health-related concerns, values and priorities. Compromising between these two forms of politics was and continuous to be unfinished business.

Discussion

In this paper, we have asked the following: What matters in infrastructuring experience within health care systems? Our approach to this question was focussed on understanding the pragmatics of making a sociotechnical infrastructure for patient experiences in a specific health care setting. Recognising technologies of patient experience as specific types of 'investment in form' with historical roots was our point of departure to explore the normative and epistemic tensions involved in establishing a national PRO database.

Our data reveal that those involved in crafting and developing the Danish PRO system seek to encode 'patient experience' in the Danish healthcare system by infrastructuring for the clinic, by infrastructuring for the organisation, and by infrastructuring for participation. The infrastructuring efforts in each of these domains involves tensions as the emerging phenomenon of PRO rubs up against existing and concurrent ways of working clinically and of enhancing and evaluating the quality of clinical care. In infrastructuring for the clinic, protagonists seek to ensure that PRO as a clinically meaningful tool is prioritised over managerial aims. This, however, rubs against the embeddedness of research and quality management as part of clinical practice. Also, what is useful clinically may involve trade-offs in terms of scientific rigour equally creating tensions with existing professional identities. Infrastructuring PRO also involves relating to organisational concerns such as the need to make care trajectories more efficient and better coordinated across sectors. But redirecting resources and expertise to issues that matter to patients also raises concerns as to the actionability of PRO data and the capacity of organisations and clinicians to respond. The installed base of sectorial powers and boundaries and existing data infrastructures provides extra challenges that bring to the fore the political and relational nature of PRO. Finally, infrastructuring PRO for and through patient participation is seen as central to the overall legitimacy of the endeavour, but in its own right introduces dilemmas when considering if PRO is truly a participatory and patient-centred tool. Further, compromises reached in any of these domains are also not necessarily aligned with each other, adding to the complexity of the work of infrastructuring PROs.

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The literature on data infrastructures for personalised health care has focussed on the implication of datafication and surveillance for practice. Looking at emergent infrastructures of personalized medicine, Barbara Prainsack (2017) has used the notion of a "surveillance assemblage" (pp. 51–55) to point to arrangements in which certain technologies and human practices together operate by abstracting individuals into data flows to be reassembled for various purposes at different times and in different places as "data doubles". More widely, scholar also points towards how the conversion of experience into a standardised set of data simplifies the meaning and significance of patient experience as a form of knowledge (Pols 2014).

While we share these scholars' concerns about the consequences of infrastructuring personal data and intensified data sourcing at large, our research highlights that the recursive balancing act that constitutes infrastructuring requires understanding the forms of normative and practical reasoning developed by those who are directly involved in collective negotiation about what constitutes 'experience' for specific purposes in specific contexts. For them, 'patient experience' is above all an epistemologically and morally unstable figure. Ellwood's dream of "a new universal language of hurting, functioning, working, interacting, and living" is not within reach. It is a key finding of our paper, that while it might be a powerful trope in gathering actors and resources, it is not easy to decide and to settle upon "what matters to patients". In this regard, CGCs negotiating how to infrastructure experience could be seen as an instructive experiment in practically handling the 'ontological politics' of patient experience. Whether the PRO infrastructures enabling the circulation of more 'thin' versions of patients' 'data doubles' will push out or transform other ways of knowing patients and engaging with such knowledge in health care are pertinent questions for further research in the application of PROs in practice.

Compliance with ethical standards

Conflict of interest On behalf of both author, the corresponding author states that there is no conflict of interest.

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