



Patient-reported data and the politics of meaningful data work

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Abstract

Patient-reported outcome data have moved from the realm of research to center stage in efforts to provide patient-centered care. In a Danish context, health authorities are seeking to promote and standardize the use of patient-reported outcome data. This involves normative articulations of what counts as *meaningful data work* in a healthcare system characterized by intensified data-sourcing. Based on ethnographic material, I suggest that an assemblage of actors, both human and technological, has accomplished the articulation of meaningful data work, with patient-reported outcome as being dependent on the active application of data in clinical trajectories—in contrast to supplying data “passively” for secondary use for research or governance. This normative articulation of “Active patient-reported outcome” legitimizes the Danish patient-reported outcome assemblage by showing alignment of the concerns of patients, clinicians and health authorities. At the same time, “Active patient-reported outcome” foreshadows challenges in making data work meaningful in local practice.

Keywords

articulation, data assemblage, healthcare policy, meaningful data work, patient-reported outcome data

Introduction

Patient-reported outcome data (PRO-data) have recently moved from the realm of health research to center stage in several healthcare systems as efforts are made to provide more patient-centered care at lower cost. PRO-data can be defined as “data on the patients’ health status, physical and mental health, symptoms, health-related quality of life and functional level.”¹ PRO-data is often highlighted for being *reported directly* from the patients via standardized and validated questionnaires. Technological advances have made possible the distribution of such questionnaires to more patients, as well as enabling more systematic usages of PRO-data for clinical and governance purposes. In a Danish context, the public health authorities have initiated the institutionalization and standardization of the clinical use of PRO-data nationally. This is an initiative which a senior researcher in the area has called “more optimistic and far-reaching than any [PRO initiative] found elsewhere in the world”

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(interview). While the subject of PROs often enters health policy discussions in relation to Value-Based Management initiatives,² this is not exclusively the case in the Danish setting. Rather, as the analysis shows, what kind of work PROs should be involved in and instigate is a matter of ongoing negotiation. In this article, I will describe the emergence of a PRO-assemblage (comprising both human and technological actors) in the context of Danish public healthcare, with a particular focus on the normative articulations of what count as *meaningful data work*, when data are sourced from patients through standardized questionnaires and on digital platforms. In a healthcare system increasingly characterized by intensified data-sourcing,³ discussions in the health policy domain are increasingly concerned with questions of data: Which data, on what? What should be provided by whom? In which form and for what use?³ These politics of data also concern—implicitly or explicitly—a politics of what counts as meaningful data work: with the overwhelming demand for more data on more people, what kind of data work, done by whom, makes sense? Showing how the Danish initiative articulates PRO as a tool to further a clinical logic and a normative vision of patient involvement, this analysis can provide insights into the way in which new tools for collecting data from patients entail negotiations of the emerging opportunities—and the burdens—of “data work.”

Data work and the data assemblage

With reference to visions of empowerment in healthcare,^{4,5} patients and citizens are increasingly enlisted as data-providers, feeding the healthcare system with data for various purposes. Framed with democratic idioms, little attention is given to the *task of providing data* as “patient work.”⁶ Talking about patients “sharing data” rather than producing data, invokes an implicit “ethic of sharing”^{7,8} and ignores the efforts it entails. Clinicians, equally, are expected to make use of new kinds of data—both the data provided directly by patients, and also the data they themselves must produce in ever greater quantities for secondary purposes. It is more widely recognized that clinicians’ engagement with data involves effort, is closely bound up with, and has implications for, clinical work.^{9,10} In particular, the field of Computer Supported Cooperative Work has contributed to this insight.¹¹ Based on Symbolic Interactionism, this tradition insists on the contextual and negotiated nature of work: what counts as work is dependent on the definitions applied and thus on the relations of power in a given context.¹² Here, I extend this interest to the way data work gets tracked and valued through the health policy processes that lay the conceptual, financial and organizational grounds for data work in everyday practice.

The establishment of new assemblages of health data actors and their subsequent negotiations and normative articulations come to shape the conditions of possibilities and spaces of agency of patients and healthcare professionals that are to engage in data work.^{3,4,13} Policies on mandatory reporting of data for quality management have for instance been shown to demand extensive documentation by clinicians, who often experience this data work as meaningless and obstructive for their core tasks and their relationship with patients.¹⁴ Also criticism has been raised of politically equating the provision of data by patients with genuine patient involvement,¹⁵ thus questioning one of the proposed benefits of asking patients to do more (invisible) data work, as in PRO.

In my use of the concept of “data assemblage,” I draw on critical data studies¹⁶ and Actor-Network Theory.^{17,18} A data assemblage can be seen as “a complex socio-technical system composed of many apparatuses and elements that are thoroughly entwined, whose central concern is the production of a data.”¹⁶ In studying the emergence of new ways of producing and using data about patients, the concept of data assemblages is useful in its insistence on seeing relation-building that may cut across and reshape traditional institutions, boundaries and distinctions. Even though data assemblages may come to be institutionalized and thus experienced as bounded, the very notion of “data” reminds us of the fuzziness of such boundaries: data are characterized by their ability to travel beyond their place

of production. To study how a new data assemblage is being established, I will follow Actor Network Theory's (ANT) general analytical principle of tracing the mobilization of actors and the articulations, negotiations and translations involved.¹⁷ I will show how this both entails alignment between heterogeneous actors in support of a clinical logic of data work, and new fragilities as the normative figure of "active PRO" paradoxically foreshadows challenges in making data work meaningful in practice for patients and health professionals alike.

Methods

In this article, I present preliminary findings from an ongoing ethnographic study of the emerging politics and practices of PRO-data in the Danish public healthcare system. The interest in looking at the emergent arena of PRO-data is linked to a wider interest in understanding the everyday experiences and institutional implications of the digitalization of health services and associated intensified data-sourcing;³ particularly those implications involving patients and citizens directly as health data "prosumers" who *produce* valuable data in the process of *consuming* digital health services.⁷

The fieldwork, which this article draws on, concerns the discursive articulation and institutional framing of PRO in the Danish public health sector. Here, the empirical material consists of field notes from participant observation in public meetings and expert groups, and a large number of official policy reports, consultancy reports, minutes from steering group meetings, newspaper articles and other documents. Interviews have been held with stakeholders from patient associations, national policymakers, technology developers, clinical and academic senior researchers with PRO expertise, and employees at the national data authorities (n 15). Following ANT's credo of "following the actors," these informants have been selected for (1) their formal involvement in activities related to the emergent national PRO efforts, such as serving as steering group members, acting as consultants, sitting in on expert groups, talking in public meetings arranged by the authorities; or (2) their active involvement in activities that they explicitly and publicly frame as related to PRO, such as working in clinical research, giving public talks on the issue and developing technical services for PRO. I have analyzed these interviews thematically with attention to the problems and purposes articulated, the normative framings and the articulation of patient participation. Quotes used in this article are translated from Danish by the author. It is a precondition for access to this highly politicized and very small field that I can, when requested, provide my informants with the highest possible level of anonymity. Therefore, some informants' identities are presented only through generic information about their position and role in the assemblage.

The emergent Danish PRO-assemblage

In Denmark, the collection and use of health data provided directly by patients themselves have been explored and expanded since before the turn of the millennium, in particular in the area of telemedicine. The arguments for asking patients and citizens to engage through digital means remain central to the national vision, as stated in this public strategy on digital health from 2013 (my translation):

Patients should have the possibility of digitally reporting their health information and measurements, making it possible that these are taken into consideration when planning the course of treatment [...] The number of routine follow-ups and simple examinations should be diminished e.g. by letting the citizen report the relevant health information digitally.¹⁹

Providing data is here framed as a *right* of patients to share “relevant information” with the health system and a *duty* of the health professionals to make use of this information to assess needs and reduce the number of consultations. A recent survey often cited by policymakers found that a large majority of Danish patients want to share their data with the health system.²⁰ Here, as elsewhere⁸ patient-generated data is potentialized as an untapped resource. In policy papers such as the one cited above, little reflection is generally given to the new kinds of extra work entailed in either providing or making use of such data. The lack of a clear-cut success on the national telemedicine initiative and a continued political aim of tapping into patient-generated data provide the backdrop for the recent national initiatives in the area of PRO-data. In the following, I will zoom in on the emergence of these initiatives and on the actors and the articulations involved.

Clinical innovation, cost-containment and “workable” patient involvement

While several Danish projects had been utilizing patient-reported data for clinical, administrative and research purposes for several years, the political interest in PRO-data only really gained traction in 2015, with a private consultancy report commissioned by a public steering group, following up on the national digitalization strategy from 2013.²¹ Analyzing in particular the experiences from projects in one region that had worked with digitally collected PRO-data for managing outpatient visits, the report concluded that a national and systematic collection of patient-reported data would enable a saving of 84 million Danish Krone (approx. 11.3 million Euro) per year.²¹ Moreover, the report argued that there would be significant quality gains, including patient empowerment.²¹ The regional, public non-profit enterprise Ambuflex, whose experiences the report drew heavily on, has since 2007 specialized in developing so-called TelePRO for the digital collection of PROs for managing outpatient treatment. Outpatients get regular, digital questionnaires to be answered at home and if the data—pertaining to health-related quality of life (QoL), activities of daily life (ADL), particular symptoms or other standardized items—indicate that all is fine, the patient will receive an automated response. If there are uncertainties or grounds for concern, a nurse will call the patient and possibly set up a consultation with a doctor. The system thus functions as a partly automated screening system aimed at reducing unnecessary routine consultations.

With the consultancy report, Ambuflex’s experiences become generalized as showcasing much broader potentials for the entire health system. Moreover, the report is continuously mentioned by informants as an important gateway to more genuine interest from government and regional officials. Various actors do however raise doubts regarding the economic optimism of the report and the scientific validity of experiences on which it draws:

There is no scientific process behind it [...] They introduced these [questionnaires] for a totally different purpose [than the research purpose for which they had been developed—Ed.]. [...] They have just jumped to the assumption that this is a good thing. (Interview, senior researcher)

Yet, shortly after the publication of the report, the budget agreement on healthcare between the government, the regions and the municipalities explicitly mentions PRO-data and mandates a national roll-out of the use of PRO in three clinical areas.²² Of political interest are both cost-containment and the potential to operationalize the “fluffy” political goal of patient empowerment:

Everybody talks about patient-centered care and user involvement [...] But what is it?! We [the health authorities] want to do it, but what are we to deliver on?! Then the concept of PRO comes along and it seems reasonable [...]. You can include the patient, but in a structured, meaningful way. (Interview with senior policymaker, Ministry of Health)

In connection with aims of patient involvement, PRO-data is articulated as systematic, collected with standardized tools, and as having its point of origin in medical research, thus translating a “fluffy” ideal into something valid and manageable in a biomedical-minded system.

Program PRO and “meaningful” PRO-data

The linking of PRO to “workable” and systematic patient involvement lays the ground for an alliance of policymakers with strong actors on the patient-side, who are already working to mobilizing knowledge and support for a more widespread use of PRO-data. The umbrella association Danish Patients initiated a project in 2015—“Program PRO”—to provide grounds for better public decision-making on how to use PRO-data to improve quality in the Danish healthcare system.¹ Where previous work had been done by the Cancer Society focusing only on PRO-data in cancer care, Program PRO was concerned with the use of PRO-data across all potential clinical domains and all health sectors. The invited patient representatives, researchers, policymakers, public executives and “PRO-experts” concluded that

The use of PRO-data should be integrated in clinical practice and in quality development. It is emphasized that it is important to ensure that patients and health care professionals find the use of PRO-data in the clinical setting meaningful and relevant. This contributes to a more consistent use in quality improvement.¹

This insistence on “meaningfulness” echoes the conclusions of the more research-based report by the Cancer Society, which equally underlined the need to ensure that clinicians find the tools “meaningful” in daily clinical practice.²³ Some clinicians in these projects had failed to look at or comment on the data provided by patients, causing patients’ disappointment.²³ Also, both reports argue, without patient- and clinician-commitment the completeness of the data for quality surveillance could become questionable. Value-based management is referred to in both reports, but clinical usefulness is argued to be a *sine qua non* for using PRO for quality purposes. The international trends toward data-driven quality management²⁴ and Value Based Health Care² influencing the Danish health arena at many levels²⁵ are in this particular initiative translated from a question of passively *extracting* patient data for quality monitoring, to a question of actively *producing* clinically meaningful data for both primary and secondary purposes. This translation implicitly acknowledges the high levels of criticism raised by clinicians and researchers toward previous attempts of quality management based on extensive documentation work.^{14,26} However, it does not consider the situatedness of data, potentially making the extraction for secondary purposes difficult.²⁷

Institutionalizing the Danish PRO initiative

The final report from Program PRO was launched at a public event in 2016 with the Minister of Health promising the government’s support for PRO as a national priority. Later that year, PRO-data featured explicitly both in the financial agreement between the government, the regions and municipalities and in the national budget.²⁸ In the national budget and under the heading of “Patient Involvement, Patient Reported Data” the funding is ensured and it is further stated that, “The purpose is to ensure that the knowledge of the patient about his or her own disease and experiences of the effects of treatment is made greater use of in treatment and quality management in the healthcare system.”²⁹

New institutional actors were put in place: the national steering group on PRO was established under the auspices of the Ministry of Health, and a PRO-office at the Health data authorities was given the practical assignment to “standardize PRO-questionnaires to patients; produce guidelines

for standardized use of PRO-data across geographical, sectional and specialty boundaries; and contribute to systematic knowledge transfer.”³⁰ Putting the responsibility on the health data authorities signals an ambition to integrate this work with other initiatives on the collection and use of health data for purposes also at an aggregated, national level, and of ensuring a sustainable national digital infrastructure for the endeavor. The PRO-office took as its point of departure the recommendations from Program PRO and has started establishing a “national questionnaire bank” for well-defined treatment areas to be rolled out continuously. This work is ongoing, involving regionally appointed clinicians and patient representatives in a number of “clinical coordination groups” (November 2017).

“Active PRO” and the primacy of a clinical logic

While notions of “quality management” had found its way into these official papers, the steering group and the PRO office have, at public events, been very specific in wanting to promote a particularly Danish version of PRO: the “active PRO”:

At the first status meeting for the national PRO-initiative, a member of the steering committee gives an introductory presentation. Calling PRO “the patient’s own registration of her health status,” he underlines the difference between “active” and “passive PRO.” Active is when the patient herself can use the data in her encounters with the system. Passive is when the patient never hears anything after having sent in the answers. He [the member of the steering committee] compares this last scenario with a case where research subjects in Greenland were discontent with the fact that researchers had left with “their data” never to give any feedback. (Fieldnotes)

The comparison drawn here clearly illustrates the normative articulation at play: “passive PRO” equates with taking patients’ data away from them. “Active PRO” denotes respect for patients’ ownership of data and that data is collected with the primary purpose of use in clinical trajectories to inform decision-making and dialogue, NOT primarily for quality management or research. Experiences from the United Kingdom, where collection of PRO for quality management had been made mandatory in a number of treatment areas, showed that clinicians did not comply with the task and the data ended up being of poor quality.³¹ Although data from “active PRO” might be rendered useful for value-based quality management schemes, the Danish protagonists underline again and again that this should not be the main purpose of sourcing PRO-data from patients: “It has to make sense to Karl Anton!” as the chairman for the steering group and senior policymaker from the Ministry of Health exclaimed at a meeting for clinicians, invoking a fictional, older patient, and urging participants to make this sentence their credo. “Active PRO” thus comes to represent the alignment of the interest of the patient as data provider and who therefore has the right to be involved, the clinician as data user, who gains “another tool in the toolbox,” and the management and state as secondary users, responsible for quality and resources, but drawn back from the frontline of data work. The normative articulation of “active PRO” thus pushes secondary uses of data temporarily to the shadows and rhetorically legitimizes more data work to patients and clinicians.

Discussion: meaningful data work in practice?

Specific data assemblages are always part of larger data landscapes¹⁶ and their boundaries are fuzzy and transgressed by systems and—of course—data. Systems and data produced in one assemblage become part of the operations of other assemblages: the technical infrastructure sought to support the exchange of PRO-data is to be integrated into an existing system supporting national

telemedicine services, and data standards are to insure that PRO-data can be used “for other purposes.” However, the boundary-making I have been interested in here is that made through political articulations of human actors seeking to define the conditions for the production and circulation of PRO-data in Danish public healthcare—and thus the conditions for future data work. At present, a temporary rhetorical demarcation has been made with the distinction between “active” and “passive” PRO suggesting that meaningful data work can be established when data can be seen to further a clinical logic and a normative vision of patient involvement. However, there are challenges to the sustainability of this boundary, which may foreshadow challenges in making the daily work with PRO “meaningful” in practice.

First of all, the difficulty of disentangling PRO for clinical purposes and PRO for managerial purposes is not just a conceptual challenge, but also a challenge which extends to the actors involved in the emerging data assemblage. A number of the actors engaged in Program PRO, in steering groups and in the clinical coordination groups that are to choose or create the questionnaires for a national “questionnaire bank” are also enrolled in activities initiated by healthcare authorities exploring Value-Based Management as a new model for quality management and financing. For these actors, the boundaries may be particularly blurred. This is most notable in relation to the clinicians involved in the clinical coordination groups, who in several cases are also responsible for clinical quality databases in their area(s) of expertise. This factor of clinical quality is seen by many as a core element in a value-based steering model. They are already highly engaged in collecting “passive PRO,” so whether the distinction between “active” and “passive” PRO is meaningful for them is an empirical question, which I will seek to answer through ongoing fieldwork.

Second, there is a different but related challenge of upholding the alignment between a clinical logic and a vision of patient involvement. The accomplishment of relating PRO to an agenda of patient involvement calls for more engagement of patients in the development of the “questionnaire bank” as well as in local adaption and implementation in healthcare practices. Many of the original projects—including some Ambuflex projects—had not initially involved patients. While often experienced as worthwhile, patient involvement is time-demanding and reintroduces different perspectives on PRO at the level of choosing or creating questionnaires and items. And furthermore, if patients have more influence on the content of the questionnaires, will these still be meaningful to clinicians working in a biomedically oriented healthcare system—many of them *also* interested in standardized data for research purposes? Only very few qualitative studies of the use of PROs in clinical practice have been made, but Essén and Oborn’s study of PRO in Swedish illness management suggests that a tension prevails between patients’ wish for data that reflect their individual symptoms and life situation, and the clinicians’ wish for standardized data for aggregation purposes—even if PRO is introduced with primarily a clinical logic and vision of patient involvement in mind.³²

Finally, the rhetorical insistence that the data work with PRO should be “meaningful” will not in itself ensure that only meaningful data work follows or that all actors experience it as such in daily practices of healthcare and everyday life. In an interview, a senior researcher with clinical knowledge says: “I think it will be pure chaos. [...] We will just get overworked clinicians who have yet another thing they have to do. Another task that comes from ‘up-stairs’.” This thus points to the risk that in the everyday practice of overworked healthcare staff, PRO—if made mandatory—will not be experienced as “another tool in the box,” but as meaningless data work similar to other unpopular registration tasks. Also, it might be relevant to consider the sheer magnitude of new data work that it could demand in practice: while the Ambuflex’s initiatives have mainly been focusing on management of outpatient visits, which is something that can reduce workload, the national initiative aims at providing PRO-tools for all “relevant” clinical trajectories across sectors. This could involve many questionnaires to be distributed, answered, collected, analyzed and put to

“active” use on a regular basis, with little knowledge at present about the clinical, organizational or social implications of such activities. Hypothetically, a patient with several chronic diseases could be asked to answer regularly—and differentiate between—a number of different questionnaires for her different diseases and clinical encounters—potentially on different IT platforms if the treatments take place in different regions. This is demanding data work, which could easily go unrecognized and bring about unintended consequences.

Implications and further research

On a general level, with this analysis I hope to have illustrated how future data work is being scripted through the policy processes and assemblage-building activities that lay the ground for practical engagement with health data in a public health system. However, the paradox of this case is that while protagonists were highly aware from early on that local meaningfulness of data work is of utmost importance, yet at the same time, in order to create a strong national initiative, they also had to find ways to align many different agendas that may not remain aligned in everyday use practices. It is an open question whether this initiative will stand its ground on the primacy of clinical work and patient involvement, or become swallowed up in other, potentially more powerful data assemblages, such as the one forming around Value-Based Management and financing. This is not to say that the data work of procuring data for managerial purposes is inherently meaningless, just that tensions arising between clinical and managerial agendas are well known—among the actors in the assemblage described and in the literature.³³

In the new healthcare landscapes forming through data intensification, PRO tools may offer metrics to assess the effectiveness of treatments more closely connected to the experience of the patient than other available metrics.¹⁵ However, further research is needed on the actual experiences of patients as users of these tools. For instance, how do patients experience answering standardized questions about their QoL on a regular basis, and when are their answers consequential for their access to services? To what extent do the questionnaires instigate reflection, self-care, worry or fear? Do PROs reduce demands for services, as promised? Or do they actually promote new sensibilities and demands for new care services? How do health professionals and health organizations integrate the use of PRO in daily practices, not least as tools of interacting with patients and with other health professionals across sectors and professional boundaries? These and many other questions should be addressed in future work on PRO tools. On a more general level, future research on datafication of health will benefit from directing equal attention to the establishment of the specific data assemblages and to the experience of those living and working at their fringes.

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