

# The Expertise Of Patient Organisations: Making Patients' Voices Heard

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## **THE EXPERTISE OF PATIENT ORGANISATIONS: MAKING PATIENTS' VOICES HEARD**

The article discusses how the Russian patient organisations work on making patients' needs, experiences, and grievances visible, acknowledged and used by state health governing officials and other experts. First, we present a health governance knowledge hierarchy that reflects different value assigned by healthcare governance actors to different knowledges. At the bottom of the identified hierarchy are the 'lay' experiences of individual patients, whereas policy-making knowledge ranks the highest. Each type of knowledge is distinguished from others with its own language, logic and, most importantly, material world and forms of action. We advance the two key arguments. First, patient organisations work to facilitate interaction between different actors and co-creation of health governance. Second, a crucial element of this work are organisational operational practices. Several major patient organisations are the key actors being recognised by state institutions. These organisations facilitate collaboration via project and event management, as well as aggregate 'lay' expertise-by-experience of their members and produce knowledge understandable and recognisable by decision-making actors. Methodologically, the article is based on the descriptive coding of available textual data of the key policy documents, legislation, methodological materials and other documents produced by the Russian patient organisations, as well as online ethnography of project activities, patient surveys, schools of patients and other knowledge disseminating vocational training, public council meetings, and other patient community engagement with state officials. In conclusion, the article summarises how Russian patient organisations strive to make their participation in health governance possible. They do so via reliance on organi-

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sational operational skills in maintaining collaborations with other actors, as well as wider knowledge production activities.

*Keywords:* knowledge hierarchy, expertise, health governance, patient participation, organisation operation

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Health governance is a result of work by many actors, such as medical doctors, state officials and, not least, patients. Patient and public involvement in health governance is a common and established practice due to a growing consensus that patient and public involvement is a normative ideal and an efficient tool to ensure the 'responsiveness' of the healthcare system to needs of its end users (Mol 2008; Callon, Rabeharisoa 2008).

In Russia, as in many other countries, legislation provides opportunities for public control of state institutions by citizens and third sector organisations (Federal Law 212), including patients and other healthcare-related actors (Federal Law 323: Art. 6, 28). Yet, Russian patients, similar to their peers in other states, still struggle and find it difficult to have their voices heard by decision-makers due to, among other things, the unequal weight assigned to the knowledge patients have, and attitudes of 'recognised experts' and professionals towards their knowledge. This article reports on how Russian patient organisations (POs) ensure that their member experiences, needs, grievances, and vision of healthcare system improvement are being heard, recognised and responded to, and what practices are seen by POs as best serving this goal, considering the existing obstacles and challenges for 'lay' everyday experiences being recognised as valuable for so-called 'systemic,' institutional-level health governance.

Epistemologically this research treats health governance as both communicative and material practices. In other words, patients and other actors involved in health governance learn not just 'managerial pidgin' or change identities, but interact with different human and nonhuman actors, and do things differently. Hence, health governance varies in spaces, objects, and methods involved. In other words, health governance and the work of patient organisations is embedded in the material world as much as in communication (see, Nicolini 2011: 602; Marres 2016; Coopmans, Button 2014).

Empirically, this article presents an analysis of documents and online ethnographic observations of interactions of the Russian patient organisations with state healthcare governing actors. The qualitative data are used to reconstruct how patient organisations in Russia problematise (not) having experiences, needs and grievances of patients being heard, recognised and responded to. We argue that patient organisations rely on organisational practices of external communication and project management, as well as knowledge production, to include their members' voices into health governance, but also ensure their own participation in decision-making as organisations.

## Patients' Contributions to Health Governance

Scholarship on contribution of patients to health governance generally agree that patient participation is both democratic and 'effective' (Mol 2008; Callon, Rabeharisoa 2008). In other words, patient participation is encouraged for normative – e.g. representation (Martin 2008; Stewart 2016) – and practical reasons: e.g., better quality of medical care (Wynne 2007; Popay et al. 2003). Patient contributions might bridge 'supply and demand' of the healthcare system, making decision-making more transparent and responsive. Patient participation also has a significant practical relevance for everyday life of people living with a disease (Pols 2014). Patients participate in various forms, such as public hearings, panels, conferences, meetings, and collaborations with doctors, pharmaceutical companies, and state institutions.

A normative and theoretical agreement on the relevance of patient participation, however, does not necessarily mean an equal and untroubled involvement of patients in health governance. A representation of this ambivalence between the ideal of responsive healthcare and the practice of channelling participation can be seen in an apparent hierarchy of various epistemes. This can be defined as a 'particular strategy... that orders the materially heterogeneous relations of the social to generate particular and distinctive patterns of subjectivities and objectivities' in the society (Law 2010: 8). Epistemes are not just a sort of ontological framework, but also situational, performative practices embedded in a specific time and space and co-produced by actors. Hence, a distrust and 'negligence' towards patients' contribution to health governance is an epistemological expression of a divide between experiential knowledge and skill, and expertise acquired via formal training and professional work, or 'experts-by-experience' and 'experts-by-training' respectively (Fox 2008; Skilton 2011). The former is an aggregation of mundane interactions and everyday practices. It is unstructured, varies from individual to individual, and is based on informal or non-formal knowledge. The latter is formal, acquired via formal educational institutions and further developed, audited, and verified within a recognised professional community. It is structured and embedded in various protocols, standards, procedures.

Experts-by-training like medical professionals (also human actors representing governmental institutions, whose expertise in governance is supported by their official position), view patients as unprepared for 'systemic work' of improving healthcare (Stewart 2016; Popay et al. 2003: 2–4). As a result, professionals, state officials, and experts (all categories are not exclusive and often go together in various combinations) are also rather reluctant to take patient 'lay' experiences – the expertise acquired via everyday practice – into account, or treat it as equally relevant knowledge (Conrad 2005; Endaltseva, Sonja 2021).

In response to distrust and gatekeeping from 'recognised experts,' state officials included, patients and POs employ different tactics to make their

voice heard. One tactic is to develop a medical expertise (Epstein 1996). Another tactic is to build expert status by 'professionalising' personal experience and everyday practices (Kerr et al. 2007). POs do this by 'producing' knowledge about needs of 'lay people' and conveying it to state officials at various meetings, events, and other interactions facilitated by POs themselves.

## Methodology

The article presents some results of a qualitative social research on patient involvement in health governance in Russia. The data consist of documents and multimedia materials (e.g. video records of the conferences and training). The analysis reconstructs Russian health governance landscape, how patients and patient organisations are constructed and self-represented. We approach documents both as a source of data and agency-possessing entities on their own (Asdal 2015). In other words, we treat analysed texts not as a transmitter of information but as a transformative and performative actor influencing social reality via 'modifying work' (ibid: 76).

We identified fifty-eight written artefacts (documents) which are indicative of health governance practices from the perspective of navigating between different types of expertise and facilitating interactions of relevant actors, both human and nonhuman. We found most documents by searching through websites of the major federal-level Russian POs which collaborate with various healthcare-related state institutions. Documents include news (4), study reports (8), methodological materials (3), self-representation texts (3), official and internal documents (23) such as minutes (17), project reports (4) and other materials relevant for patient involvement in health governance in Russia, including audio-visual materials and legislation. The relevant artefacts together describe but also make up POs' work on claiming expertise relevant and needed for participation in the health governance.

'Methodological' materials by all-Russia POs and their partnering think tanks (all names in the article are anonymised) are particularly relevant for reconstruction of how POs work to make themselves heard and listened to. They position POs as skilful in communication, management, projects, and 'government relations.' Overall, analysed documents present and embody principles and practice of POs' involvement in health governance, their position, methods of securing recognition as experts and ensuring that patient and POs' interests are incorporated in health governance.

The method of analysis is a thematic content analysis of the aforementioned artefacts. It combines both descriptive and interpretive coding (Flick 2013: 152–154). Altogether, in a two-stage thematic coding procedure, forty-nine codes were identified and grouped in thirteen code groups. The first stage coding involved theory-based interpretative coding, focusing on topics of public participation and informality, with a recurring topic of professionalisation of

the third sector. The second stage coding was based on a deliberate analytical exclusion of the professionalisation theme, with empirical data-driven descriptive coding. At this point, several major themes related to various expressions of expertise emerged. This includes, among other things, 'being bold' (status and visibility of the organisation), 'constructive opposition' (pacification of patients and adoption of the 'professional' language and practices), 'managerialism' (operation-oriented practices), and 'mediation' (a key identity and position of POs in health governance).

In line with Kristin Asdal's epistemological approach (2015), we see documents not just as a source of data, but as artefacts embodying and performing their own content. Methodological materials, usually in the form of reports created in the framework of the state-funded projects, are developed by the leading Russian POs. They cover topics such as what are the most relevant legislative and policy elements framing the current Russian healthcare system and its governance, how to engage the state, how to use public councils' institutions for patients' good, how to manage projects and run third sector organisations. These documents present and are products of particular practices: professional, 'constructive,' emotionless, based in knowledge and skills in law, biomedicine, and state governance. To be produced, reports, applied social research, policy recommendations, official documents, procedures, and minutes require skills mentioned in the same documents.

The vocational training infrastructure – such as patient schools and various courses and meetings for patient organisations' activists, business coaches, corporate trainers, and healthcare experts-by-training – is a direct result of the methodological recommendations. It aims at disseminating organisational skills (project management, involvement in collaborative spaces, external communication) among a wider patient community (Voß et al. 2021). These organisational skills, though perceived technical, is a watershed between 'layness' of experience-based expertise and work associated with expertise-by-training (Fox 2008).

### **Hierarchy of Knowledge of the Russian Health Governance**

In analysed documents POs define health governance as writing documents, finding evidence, collecting and analysing surveys and data on hotline calls, applying for social project grants, making reports, presenting them at various collaborative spaces such as public councils. The goal of all this work is to ensure voices of patients being heard, taken into account and used in decision-making.

Key 'methodological' documents published by the umbrella patient union describe best practices (also dubbed 'technologies') of public participation by socially oriented NGOs (D 58) and of involvement in public councils, the key state-sanctioned and state-affiliated consultative bodies in Russia (D 44 and

D 47). According to these documents, there are several interest groups involved in health governance in Russia (D 58: 7). First, there are executive and legislative governmental institutions at the federal and regional levels. These state officials are responsible for health governance and their skills and knowledge are positioned as the most valued when it comes to health governance. At least, state officials are for POs on the top of the list of potential 'stakeholders' to collaborate with. 'Administrative' abilities mentioned as necessary for patients to be recognised by state officials as equals and relevant partners include several skills and knowledge. These are general proficiency in formal and informal state administration, ability to analyse and make policy and legislative documents, ability to speak 'oficese' (a language of bureaucracy with all its 'dryness' and a very specific 'formalistic' vocabulary) and knowledge of normative foundations behind state governance (e.g. financial considerations 'beat' scientific conclusions or biomedical treatment protocol requirements): thus, '[i]nsufficient legal literacy and low competencies in governance' is in the list of obstacles for POs' involvement in health governance via public councils (D 58: 84).

Another crucial collective, according to one of the most important documents 58 (page 7), is the medical professional community. Their biomedical expertise and the ideal of evidence-based medicine are uncontested by POs, as mentioned in the PO documents: NGO learns from the medical community the information 'about particularities of the medical assistance' since 'doctors are the source of information, engine, and motivator' and 'they explain us an essence of the treatment' (D 58: 13). Medical professionals' authority is recognised equally in POs' methodological documents and news articles, state normative acts, and various treatment procedures and standards. At a broader level, a recognition of medical expertise is part of the wider 'positivist' episteme or recognition of the dominance of 'science' and 'objective scientific knowledge': 'For objective assessment of the current issues in the first aid provision we chose entities, which are situated at the equal distance from the regional centre' (D 47: 27).

'Objectivity' in POs' work attempts to emulate scientific knowledge production work. This is particularly visible in conduct and reference to surveys and experiments, lean towards quantitative indicators, and other similar epistemic work. Patients' individual knowledge, in line with state officials, medical doctors, and other experts-by-training, is presented by POs as valuable but requiring additional work before being incorporated in the body of knowledge informing health governance.

At the low bottom of the Russian health governance epistemes hierarchy created by normative acts, policy documents and even methodological materials by POs themselves, is individual sick body experience and an experience of being a patient (meaning living with a disease and turning for help to the healthcare system). This knowledge is a starting point for patients organising or joining NGO aimed at protecting their rights. Methodological materials

describe how to 'level up' or 'develop' from that 'mundane' and 'initial' stage – starting from creating an NGO up to becoming public experts and valuable partners for various experts-by-training involved in health governance. Recommendations on how to achieve this take pages of numerous 'methodological' documents but can be broadly summarised into two main domains: organisation operational capacities (ensuring financial stability, communicative and managerial skills, establishing and maintaining strategic partnerships, organising events and spaces for collaboration) and knowledge production about needs of the patients represented by the PO. Proven capacities in both domains – according to POs' documents – is a key for making voices of patients heard and taken into account by policy-making and policy implementing governmental institutions.

### **Patient Organisations' Work to Participate in the Health Governance**

Analysed documents put forward a problem POs face when trying to influence health governance. Namely, 'lay' patients are not part of the decision-making expert community and have little to no access to health governance. This is despite governmental institutions, especially at the federal level, being shaped by the 'public control' legislation which requires participation of the public in quality assurance of the governance.

To overcome institutional and infrastructural limits to patient participation, POs employ various tactics within the aforementioned domains of developing organisational operational capacities and engagement in knowledge production about health care matters of collective concern. To begin with, synthetic knowledge of patients' needs is created and presented to state officials. It is formulated in forms acceptable to the latter, such as complaints, reports, policy notes, and presentations referencing biomedical and scientific knowledge. Moreover, offices in which the information 'should' be presented according to POs' recommendations is 'emotionless' and uses technical terms and an order of words invert to the 'colloquial' Russian language:

A specificity of a choice of a *stacionar* [inpatient facility] in this case – i. e. a choice of medical organisations for a provision of specialised medical assistance in a planned form [inverted order of words] – is described in points 13–16 of this order [a reference to the normative document] (Website 1)

Speaking the same language as state officials and health experts is aimed at joining expert debate by producing arguments persuasive for experts-by-training. At the same time, POs frame themselves as 'representatives of the patients'. Having direct access to needs, grievances and issues on the ground – in combination with the ability to formulate it 'constructively' – is presented as a unique resource POs possess.



Hence, POs collect, aggregate, and analyse individual experiences to identify issues, which later could be presented as 'systemic' that is concerning wider groups of population. Notably, POs justify the need for produced knowledge by creating a sense of 'white spots' in knowledge about healthcare: 'there is an urgent lack of aggregated evidenced information of the issue. Such information is necessary for justified decision-making by representatives of legislative or executive branches of power' (D 44: 114). Quote from the methodological material on how POs can contribute to decision-making outlines 'lack' of summarised knowledge about patients' needs and defines a matter of shared concern as such. POs are those to fill the gap. They have to find and present information so that decision-making would be 'justified' (Rus. *obosnovanyi*). In other words, POs try to position their own expertise as necessary for decision-making to be efficient, qualitative and productive. In this way, POs position themselves and are positioned as knowledge producing actors, who have a unique access to interests of healthcare end-users (patients), but also have a profound experience and knowledge in facilitating and maintaining collaborations between stakeholders.

In addition to the interaction with other stakeholders, POs also create a PO community. The work of producing knowledge includes not just summarising data for state officials, but also creating a patient organisations' community. POs do so via maintaining infrastructure of unofficial and semi-official vocational training to spread knowledge on how patients can organise, manage projects, raise funds, and communicate with stakeholders:

A project gives a kern, basics. Then you use your personal experience like knowledge, skills, people, and network. It is not enough being devoted [to PO work]. It would lack the most important: it is not written on the paper. Then, if emotions and devotion are combined with personal patient knowledge and expert knowledge, and put on paper, then [it becomes an] efficient instrument (Doc 54).

Learning how to do projects – which is a skill not specific to patients and their experience – is seen by the quoted participant as a key for collaboration with state officials. The latter is the third domain of work by POs. POs accumulate financial resources and establish coalitions with other stakeholders to raise their own visibility and 'prove' their own sustainability as organisational entities. This, eventually, has to ensure recognition and status among experts-by-training involved in health governance, which in practice is being expressed in invitations to participate in collaborative spaces like public councils and working groups within governmental institutions.

Notably, it is not just 'speaking' the same language or operational stability in themselves, that is to secure a place for POs and, by proxy, patients in decision-making. Instead, it is a co-creative work done in co-presence what matters: 'A social effect of major public hearings is a rapprochement of the patient community with the state authorities, the establishment of more trusting working relationships' (Doc 58: 33).

Rapprochement is a major goal for patient organisations. It is a process, which leads to recognition of their work as 'expert.' To fit in, POs incorporate expertise-by-training in their practice, expressed in various formal documents, aggregation and analysis of patients' opinions, procedures, reports, policy notes, briefs, minutes, articles, and legislative proposals. This practice channels patient and public involvement in a very specific direction:

In order to fight 'aggression' of patients, patient 'extremism,' there was preliminary work done on educating patients on methods of being constructive. Unfortunately, not everyone could get rid of [extremism] and, respectively, participate in the project. We have to work a lot with these people in the future (Doc 53: 54).

In other words, a methodological infrastructure of organisational practices and knowledge production embodied in organisational operational activities, vocational training, and existing collaborative spaces is the only form of patient participation, which is framed and counted as a 'right' and 'acceptable.' In this regard, identified 'constructiveness' and 'professionalism' themes are central for the work of equating patient involvement to accepting and supporting the Russian healthcare as it is, and avoiding emotions or conflicts with experts-by-training. In its turn, 'extremism' is an opposite of both, being an umbrella term for any hostile, subversive action, be that using profanities during the appointment with doctor, or organising unsanctioned meeting in front of the regional Ministry of Health.

## Discussion

'HIV is a virus, not job qualification,' wrote Elizabeth Pisani (2010: 105) in her critique of unconditional support to patient involvement in public health. The same line of argument is used by the Russian state officials (and at least some other experts-by-training) on patient involvement in health governance. In general terms, bigger Russian POs agree with this statement as well, criticising 'lack of' legal, administrative, organisational, medical, and other knowledge among 'lay' patients, viewed by them as necessary for productive involvement of minor self-help POs.

The analysed methodological documents not just describe a desired reality, but they also perform it, being part of the infrastructure of the Russian POs' participation in health governance. In these documents, patient expert community – a leadership of several larger POs – and their partners (other NGOs, several think tanks, and a community of trainers and coaches) offer a methodological framework how 'having a virus' might become 'a job qualification' of *obschestvennik* (third sector professional), 'public expert' (*obschestvennyi ekspert*), and PO leader participating in health governance. Two interlinked domains of work exist to achieve that for the sake of patient voices being heard as an initial goal (later in the process various situational tactical goals, such as maintaining organisational operation, emerge).

Expertise acquired by patient organisations' members includes non-formal and vocational training in basic law, medicine, governance, as well skills in communication, project and event management, and running NGO. This covers organisational capabilities of POs and their leadership. Another part of the POs' expertise are skills in working with members, supporting them in protecting their rights, and in a meantime aggregating information obtained via complaints from individual patients, signals about mistreatment, failures to comply with the legislation, or analysis of 'systemic' issues performed by the patient experts based on their own judgement.

Resulting expertise of POs transform patients' lay experience into 'projects,' or a practice embedded in projects. One can say that patient life-worlds shift from hospitals to conference rooms. 'Projects' become a source for expertise recognition and are used by POs to present project results to governmental actors. As a result, a specific form of 'constructive' collaboration between governmental actors and POs is sought to emerge as an ideal form of public participation, according to the documents produced by POs. The respective constructiveness is embedded in written documents, project managerial practices, quality assurance of procedures, analytical skills, and knowledge prescribed by methodological documents. At the same time, Russian POs – capitalising on their recognition as experts on a par with other healthcare governing actors – seek to position themselves as managing in bringing voices of patients to state officials through their findings, ideas, and suggestions how to address aforementioned issues as defined by the patient communities.

## Conclusion

This article outlines the role of organisational practices and knowledge production in self-representation and infrastructure of the patient participation performed by the methodological documents. Inspired by the documents-as-actors approach (Asdal 2015), we had analysed methodological documents on third sector work and involvement in health governance produced by the leading Russian POs, as well as other relevant textual data such as news articles, legislation, and project reports. As a result, we were able to show how the most prominent POs in Russia work to make patient voices heard by governmental actors. Importantly, they believe that adaptation of 'lay knowledge' is needed before it can be incorporated into the decision-making.

As a result, POs' 'methodological documents' create a particular epistemological framework for public participation aimed at ensuring expert status for POs, as this in turn allows adapted 'lay knowledge' to be presented and taken into account by state officials. This framework is dualistic. Analysed documents refrain from questioning authority of medical professionals, use 'bureaucratic' language and logic (oficese), and generally promote development of expertise via various certification programmes (e.g. public experts), vocational training, self-education, and peer support among patients. In this way POs reproduce a dominant knowl-

edge hierarchy, in which state administration, scientific, and biomedical epistemes dominate patients' experiences of living with a disease. This work transforms and changes patient experiences into forms acceptable for the 'recognised' experts, in particular state officials. At the same time, POs continuously insist on the idea that the everyday experiences of patients, their everyday bodily and social knowledge, are crucial for decision-making and cannot be ignored.

This dualistic and diverse work by POs is a combination of knowledge, practices, and materiality involved in the process of mediating between different actors and shifting between different epistemes. Specifically, a presented work of making patients 'expertise-by-experience' (Fox 2008; Skilton 2011) relevant for 'experts-by-training' includes two key domains, namely, building organisational capacity and knowledge production. The first domain includes managerial and communication practices of engaging various actors, such as project management, event management, and establishing strategic collaborations with other actors. These practices are embedded in various official documents and are propagated by the vocational training and other forms of epistemological work of creating and maintaining a wider patient community and other third sector actors. The second domain is knowledge production, which is being done with the help of the aforementioned organisational work. It is the practice of identifying issues, aggregating complaints and other analysing and summarising surveys and legislation, making presentations at meetings with governmental actors, and doing other work of sharing epistemes of experts-by-experience with experts in a way acceptable to the latter.

A specific kind of expertise emerges in the process. This expertise of POs is mediatory and bridges expertise-by-training with expertise-by-experience, being a crucial driving force for patient participation and their voices being heard. What implications and repercussions this expertise has for patient knowledge, what place it holds in health governance, and what is being shaped and produced as a result, is a matter for further research, and might add to understanding of how health policies operate, how patients' publics come about, and what matters of collective concern in health care are.

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