



**HAL**  
open science

# The work of composition: Situated articulation of visible and invisible work within patient organisations

Alexandra Endaltseva

## ► To cite this version:

Alexandra Endaltseva. The work of composition: Situated articulation of visible and invisible work within patient organisations. *Social Science & Medicine*, 2024, 344 (116659), 10.1016/j.socscimed.2024.116659 . hal-04453856

**HAL Id: hal-04453856**

**<https://hal.science/hal-04453856>**

Submitted on 7 Mar 2024

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

**\*pre-print\***

Social Science & Medicine 344 (2024) 116659



Contents lists available at [ScienceDirect](#)

**Social Science & Medicine**

journal homepage: [www.elsevier.com/locate/socscimed](http://www.elsevier.com/locate/socscimed)



## The work of composition: Situated articulation of visible and invisible work within patient organisations

Alexandra Endaltseva <sup>a,b</sup>

<sup>a</sup> Centre d'étude des Mouvements Sociaux (CEMS), EHESS/CNRS UMR8044/INSERM, U1276, France

<sup>b</sup> Centre d'étude et de Recherche Travail Organisation Pouvoir (CERTOP), CNRS UMR, 5044, France

**Alexandra Endaltseva, “The work of composition: Situated articulation of visible and invisible work within patient organisations”, *Social Science & Medicine*, Volume 344, 2024, 116659, ISSN 0277-9536, <https://doi.org/10.1016/j.socscimed.2024.116659> (<https://www.sciencedirect.com/science/article/pii/S0277953624001035>)**

## Abstract

Patient organisations (POs) play a significant role in the transformation of contemporary health systems. This article concentrates on the mundane and invisible work that enables and maintains POs, including the contextual inscription of such work and its relational becoming with visible practices. Grounded in ethnographic study within the Russian Multiple Sclerosis Society (RuMSS), I analyse how visible and invisible work are articulated in particular situations. Through this analysis, I bring forth the work of *composition* – the continuous situated work of putting together a PO, with care for heterogeneity of its visible and invisible practices and without an expectation of a predetermined result. The strategically visible work builds up RuMSS expertise, making it a legitimate mediator between different health actors. Meanwhile, the invisible tactics maintain the internal porosity and flexibility of the PO, allowing its members to escape surveillance and achieve efficacy despite strategic limitations. The articulation of these two streams of work within a given situation is a specific invisible practice performed by the RuMSS members – the *composition work*. This work requires collective and embodied sensitivity to the effects of making work (in)visible in specific time-spaces or *chronotopes*, and it manifests a modality of care within POs.

## Keywords

Patient organisations ; Health movements ; Invisible work ; Composition ; Russia ; Multiple sclerosis ; Multiplicity ; Care

## 1. Introduction

Patient organisations (POs) have been on the rise throughout the 20th century, mobilising societies for change in biomedical research agendas, health governance, expert hierarchies, and illness identities (Barbot, 2002; Callon and Rabeharisoa, 2008; Dodier and Barbot, 2008; Epstein, 1996, 2008, 2016; Landzelius and Dumit; Rabeharisoa et al., 2014). POs differ widely in their origins, operational models and mechanisms, historical and geographic context, the medical conditions they stem from, and the commitments of their members (Akrich et al., 2014; Barbot, 2006; Epstein, 1996, 2016; Rabeharisoa, 2003). Their commonality as a social

phenomenon can be presented as the articulation of collective health condition-related identities with the mobilisation of experiential knowledge and political action (Rabeharisoa, 2006). To happen, it requires the coordination of multiple streams of work, both externally and within the organisations.

The social science literature (particularly Science and Technology Studies) provides insights into the organisation of heterogeneous work that POs perform to influence politics, science and technology, policy, and culture (Epstein, 2016; Landzelius and Dumit; Rabeharisoa et al., 2014). However, less research attention has been attributed to the mundane invisible practices of maintaining POs. In this article, I delve into this neglected work within POs, inspired by a feminist commitment to care for what is overlooked and undervalued in research descriptions of social matters (Puig de la Bellacasa, 2012). I attend to the underlying work that renders possible and maintains POs' external activities as they make visible their needs (Holavins and Zvonareva, 2022) and, more globally, change health systems (Callon and Rabeharisoa, 2008). To do so, I draw on Star and Strauss's (1999) problematisation of how visibility and invisibility operate in different conditions of work and what repercussions this may have for both equity and efficiency. To this problematisation, I join de Certeau's (1990) political reflection on everyday life practices and Latour's differentiation between critique and *composition* of heterogeneous parts, in favour of the latter for the building of a common world. This leads me, in fine, to question how visible and work within patient organisations is articulated with fluid and invisible practices of POs' members, within specific situations and arrangements.

I explore the above-mentioned question through the empirical case of the Russian Multiple Sclerosis Society, one of the oldest and most prominent POs in Russia. On the one hand, this case aligns with Epstein's (2008) call for addressing non-Western health movements. On the other hand, it allows observation of how POs' visible and invisible practices coemerge with socio-political and economic transformations and political surveillance (Temina et al., 2023; Endaltseva et al., 2021), which is particularly insightful for studying health movements. The upcoming sections introduce the theoretical background of the article and its methodology. I then situate the Russian Multiple Sclerosis Society (RuMSS) in the Russian medical context and move to discussing how work is strategically rendered visible and what kind of practices are

silenced within the RuMSS. I elaborate on the interplay between visible and invisible work through two ethnographic happenings. I discuss how visible and invisible work is articulated in the specific context, arguing that this articulation is, in itself, a form of invisible *composition work*. I also discuss the consequences of composition work and other invisible tactics for local efficacy and care, concluding with what composition work can contribute to a further understanding of POs.

## 2. Theoretical background

Discussing different ways through which patients organise into political movements, [Landzelius and Dumit](#) brought attention to the heterogeneity of health activist groups and to the “insistent heterogeneity” (ibidem: 535) of the patient as a category and as a site for socio-political interrogation around health matters. One of the cases feeding into this conceptualisation is [Barbot's \(2006\)](#) study of how different, and even competing, meanings of patient activism coexist in the work of different HIV/AIDS associations in France, emerging within a particular socio-historic context.

Another direction in making sense of POs' internal and external heterogeneity can be found in the work of [Epstein \(2016\)](#) who argued that “what we think of as “patient activism” is often relatively hybrid and fluid, with manifold goals and potentials for connection with other advocacy groups and movements of various sorts” (247). Analysing health movements in the United States, [Epstein \(2016\)](#) identified different ‘linkage mechanisms’ - coalitions, cooperations, and cross-breedings - which interconnect disease-specific activism or ‘disease constituencies’ and integrate them into larger social movements, such as civil rights or feminist health movements.

[Akrich et al. \(2014\)](#) and colleagues ([Akrich et al., 2014](#); [Edwards et al., 2014](#); [Moreira et al., 2014](#)) directed attention to “what POs do” ([Akrich et al., 2014](#)) and the many techniques and devices ([Moreira et al., 2014](#)) they use to influence health agendas, become recognised as legitimate stakeholders, and instigate changes. The authors proposed a concept of “evidence-based activism” “to capture the variety of patients' organisations, users', and activists' groups

forms of engagement with knowledge” (Rabeharisoa et al., 2014, p.114). The ‘evidence’ here is a “mediating tool between knowledge and expertise” when patient groups “articulate credentialed knowledge with experiential knowledge to make the latter politically relevant, e.g., to capture other stakeholders' interests and raise health issues” (Rabeharisoa et al., 2014, p.115).

The above-mentioned research form two foundational pillars for the theoretical background of this article. First, patient organisations are simultaneously heterogeneous and unified in practice, which points to their multiplicity (drawing on Mol, 2002). Put differently, there are many possible ways of (re)enacting, embodying, and/or accounting for patient activism, depending on a given situation and its relational dynamics. Mol (2002) argued that multiplicity involves more than a mere plurality or grouping of things or occurrences; instead, it encompasses the apparent paradox of coexisting multiple and singular aspects and the engagement of coordination work through which things “hang together” (ibidem: 83). The latter informs the second theoretical pillar: patient organisation is a process, a coming-together-in-practice, a locally specific instance in the articulation of multiple works addressed both to external stakeholders and internal relational links. In this article, I build on this theoretical background to propose that patient organisations are maintained by the situated articulation of visible and invisible work, which I call *chronic composition work*.

The notion of invisible work I draw from the work of Star and Strauss (1999), who explored the relational transformation of visible and invisible work, its promises and dangers, and negotiations concerning work's status. Invisible work refers to informal and fluid tasks 'behind the scenes', including 'articulation work' (Strauss, 1985), which maintains cooperations of heterogeneous actors and tasks, especially in unpredictable and non-standard situations. Star and Strauss (1999) provide valuable insights for understanding work within patient organisations, particularly considering the marginality and multiplicity of patient activism:

the relation between invisible and visible work is a complex matrix, with an ecology of its own. It is relational, that is, there is no absolute visibility, and illuminating one corner may throw another into darkness. For every gain in granularity of description, there may be increased risk of surveillance. In the name of legitimacy and achieving

public openness, an increased burden of accounting and tracking may be incurred. The phenomenon is one of trade-offs and balances, not absolutes and clear boundaries (Star and Strauss, 1999: 24).

This focus on the invisibility of work allows me, first, to address how POs operate in controlled and politically sensitive settings (such as Russia), and second, to bring scholarly attention inside the POs, to often neglected and mundane work that keeps them afloat. To deepen these points, I cross the notions of visible and invisible work with de Certeau's (1990) argument that everyday practices (walling, talking, eating) and opportunistic situated tactics allow for an escape from dominant controlling institutions and ruling structures. What de Certeau (1990) adds to understanding invisible work is sensitivity to how the (in)visibilities of work interlace with hegemonic (and often oppressive) dispositions. In other words, how mundane and neglected 'tactics' (ibidem) of POs' members allow POs to escape control and surveillance, without opposing 'strategic' (ibidem) work that makes them legitimate, credible, and fit for the institutional rationality of the healthcare system.

To gain a deeper understanding of this point, I draw on Latour's (2010) notion of *composition* enabling me to consider how multiple work and workers are 'hanging together' in the construction of a 'common' yet inherently heterogeneous health agenda. Latourian composition entails "the task of seeking universality without presuming that this universality already exists, waiting to be revealed and discovered" (ibidem: 474). In contrast to critiquing the suppression of certain types of PO work (e.g., local work) in favour of others (strategic work, for instance), the compositionist approach directs attention to the ongoing process of "the search for the common" (Latour, 2010:488) without a predetermined endpoint, acknowledging the "certainty that this common world has to be built from utterly heterogeneous parts that will never make a whole, but at best a fragile, revisable, and diverse composite material" (Latour, 2010: 474). Examining POs through the lens of the composition of visible and invisible work allows me not to take for granted the 'togetherness' of POs as they work towards making their concerns visible (Holavins and Zvonareva, 2022) nor the inherent possibility within this togetherness.

Bridging the composition of visible and invisible work with the local situatedness of work and practices, I ultimately propose that visible and invisible work, and their interrelation, co-emerge within specific time-spaces or *chronotopes* (for example, the collapse of the Soviet Union vs later Putin's regime). The term *chronotope*, borrowed from Bakhtin (1981), signifies that certain time-space configurations may contain patterns of visibility or invisibility. This implies that socio-material arrangements of local time-spaces embed specific patterns and even an affective charge of practices, facilitating collectively shared and embodied experiences of work. Similar to Latour's compositionism (2010), deeply rooted in artistic, literary, and performative practices, the chronotope as a notion emerged in Bakhtin's literary work and became appropriated, among others, by the social sciences (see Agha, 2005, 2015). Although the use of this notion in this article is limited to a sensitising concept (Clarke and Star, 2008), it allows for highlighting local arrangements (Mol, 2002) and the collective operation of both POs' strategies and creative tactics of their members. It also enables analytical attention to the particularity of Russian POs, including their role in the post-Soviet negotiation of the key terms and figures of the new Russian healthcare system.

### 3. Methodology

This article is constructed from materials gathered during ethnographic work within the RuMSS and the Moscow MSS, conducted as a part of my PhD project. The fieldwork was performed in person and online. Entrance to the RuMSS was facilitated by an endorsement letter from a former RuMSS general director whom I knew from my previous work in Russia. It took me almost 5 months and several additional endorsements to gain access to the regional Moscow MSS. Given the non-democratic setting of the country and the tensions concerning international collaborations, having Russian nationality facilitated field access.

The fieldwork consisted of:

- - 15 months of in-person participant observations of the RuMSS and the Moscow MSS work, during congresses (2 All-Russian Patients' Congresses and 2 RuMSS congresses),

2 patient schools, 5 rehabilitation events (including everyday happenings at the rehabilitation center), community events, and mundane tasks. The timeframe was: June–August 2016, April–September 2017, November–December 2017, June–August 2018, and November–December 2019. The field notes were dictated on the voice recorder, transcribed, and systematised using the project management application *Trello*.

- -  
15 key informant interviews spread out through multiple encounters at the various stages of fieldwork (online and in-person). The informants were selected via convenience and snowball sampling. The interviews were also recorded, transcribed, and logged into *Trello*.
- -  
Organisational documents of the RuMSS and the RUP: 4 methodological documents, 11 internal protocols and research designs, the RuMSS and the RUP websites, the RuMSS patient forum, 10 academic publications, including Yan Vlasov's habilitation thesis (Vlasov, 2006), and an open-access book written collectively by neurologists and the Moscow MSS society members (Valyukh et al., 2018).
- -  
Volunteering work at the International RuMSS department: translations, summaries of the international MS news, communication with the MS International Federation (MSIF), and interpretation for the Russian delegation during the London MSIF meeting in September 2017.

The data were analysed in two stages, with back-and-forth oscillation between data collection and analysis, and refinement of the research questions ‘in action’ (Charmaz, 1990). Following the first three months of in-person participant observation, I have analysed the data guided by the social worlds “theory/methods package” (Clarke and Star, 2008), which allowed me to account for the collectiveness of POs and the lack of previous research on POs in Russia (Endaltseva, 2020). Some of the sensitising concepts I used were ‘*chronotopes*’, ‘*commitments*’, ‘*work objects*’. On this stage, I built situational maps (Clarke, 2003) that would allow me to generate more specific research questions, such as the question of work. The second stage included qualitative content analysis. I first coded the transcribed data through descriptive coding (some

resulting codes were ‘like cockroaches’, ‘we have nothing’, etc.), and later added interpretive theoretical coding to arrive at the concepts, such as ‘composition’.

The study on which this article is based has been reviewed and approved by the ethics evaluation committee is Inserm, the Institutional Review Board (IRB00003888, IORG0003254, FWA00005831) of the French Institute of medical research and health, opinion number 17–367. The ethical procedures included the collection of written and oral informed consent which asked if participants want to appear under their real names or pseudonyms, and in which situations; exclusion of personal data (age, address, etc.) from written materials; attestation of no conflict of interest and my academic liberty, and secure storage of field material.

#### **4. The emergence and transformations of the Russian POs**

The emergence of Russian POs, like other public organisations in the country, proceeded alongside austerity politics, the shock economic and social reforms, the rise of mortality rates, and the deficit of goods, including medicaments (Endaltseva, 2020, Endaltseva et al., 2021) after the dissolution of the U.S.S.R. The end of the 1980s to the beginning of the 1990s was characterised by the collapse of the Semashko universal healthcare model, which included the transition to the public/private healthcare system and a decrease in access to care and treatments (Endaltseva, 2020; Zvonareva and Horstman, 2018). As ‘emergent concerned groups’ (Callon and Rabeharisoa, 2008: 231), the first Russian POs were concerned not only with the state of affairs in their ‘disease constituency’ (Epstein, 2016), but globally with how to reconcile the legacy of the centralized Soviet health system with the neoliberal transformations (Endaltseva et al., 2021).

Russian POs first appeared in the 1980s–90s as local peer support groups uniting persons living with life-threatening chronic and rare illnesses (multiple sclerosis, haemophilia, onco-haematological illnesses, Hunter's disease, etc.). In the 2000s, they grew into alliances of patients, carers, health professionals, and social technologists (in the case of the RuMSS), riding the wave of stabilised economic liberalisation (Endaltseva, 2020). These alliances (some taking

up the all-Russian scale) were first prompted by a common need to access new treatments and tightened up by the evolution of health markets, similar to how it happened in France (Callon and Rabeharisoa, 2008). Later, in the 2010s, disease-centred alliances expanded into cooperations between the different POs, leading to the formation of the Russian Union of Patients (RUP), founded jointly by the presidents of the RuMSS and the Russian Haemophilia Society. Following the solidification of Putin's regime, the RUP and its member POs began to secure a 'mediator' position between the government, health institutions, pharmaceutical and medical producers, and patients.

Russian POs today are public organisations founded and maintained by their members, in the pursuit of their common interests. Some of them have the special status of a *public organisation of invalids*, meaning that 80 per cent of the members have an officially acknowledged disability (this is the case of the RuMSS). Russian POs operate in three forms, depending on the scale of their work: regional, interregional, and all-Russian (uniting regions into a 'federation'). Among the latter, the RuMSS is one of the oldest and one of the first to unite regional MS organisations into a 'federal' structure. The roots of such a federating dynamic are in the territorial composition of Russia – a federation of over 80 territories that span through eleven time zones, from tundra to deserts.

Despite the considerable differences between Russian territories - environmental, economic, demographic, cultural, and infrastructural – they are governed centrally, with a concentration of political and financial power in Moscow and local corruption (Lityyak et al., 2015). Becoming an umbrella structure for the 48 regional MS societies (MSS), the RuMSS responded, on the one hand, to the Soviet legacy of regional specificity, and, on the other hand, it coordinated activist activities with governmental strategies of a 'strong state under a strong leader' (Endaltseva, 2020). This was an important change to legitimise the RuMSS activities among stakeholders (especially, governmental officials). On the other hand, it pushed the local concerns of patients-activists in the regions on the outskirts of organizational concerns. I will return to this point in the next section.

## 5. Results and discussion

### **5.1. Rendering visible certain practices: strategic work of gaining legitimacy and credibility**

Multiple Sclerosis (MS) is a progressive lifelong condition that affects the brain and spinal cord by damaging myelin, a fatty cover for the nerves. The loss of myelin causes sudden symptoms, from loss of mobility to extreme fatigue, fluctuating randomly between the periods of remission and exacerbation. MS symptoms produce disabilities, disempowerment, loss of employment, and difficulties in prognosis (especially in the progressive form) (Mazanderani et al., 2018; Nicolson and Lowis, 2002; Valyukh et al., 2018). While not resulting in a cure, the existing treatments (Disease Modifying Therapies or DMTs) ease living with MS; however, they might instigate severe side effects and thus must be personalised and taken on a continuous basis (ibidem).

In Russia, similar to other countries (Nicolson and Lowis, 2002), MS is typically diagnosed between 20 and 40 years old. Therefore, MS patients are more likely to engage with the work of POs; the state is interested in creating conditions for an “economically active population” (RuMSS general director, personal communication, November 2016), and pharmaceutical companies can develop long-term relationships with their clients (Valyukh et al., 2018). Embedded into the economic stabilisation of the early Putin's regime and accompanied by the arrival of new treatments on the newly formed Russian market, these practical specificities of MS informed a major strategic stream of work within the RuMSS. This work concerned achieving universal and free DMT coverage (subsidised by the state) and ensuring a large variety of the DMT options.

In practical terms, this entailed not only externally-oriented actions such as lobbying the government but, most importantly, the organisation of internal work of the RuMSS and the standardisation of practices across a plethora of regional activist organisations. During the early 2000s, the strategic imperative to organise and streamline work brought together dispersed MS societies, forming the first substantial player in the Russian healthcare arena – the RuMSS:

*Doctors from Samara [referring to Yan Vlasov, a neurologist specialising in MS and later the founder of the RuMSS] and social technologists [referring to Mikhail, a social technologist and later the founder of the Social Mechanics firm, a consulting and research agency collaborating with the RuMSS] compiled the best practices and practical examples from various MS societies across the country. They organised these practices based on theoretical knowledge from sociology and business management. Building on this foundation, they commenced training active patients nationwide on how to build dialogues with ‘the power’, manage organisational budgets, fundraise, work with the media, and forge alliances and collaborations. (...) Business trainers and social technologists readily collaborated, expanding their expertise to encompass an entirely new entity – public organisations. The expenses for the trainers' services or logistics were covered by pharmaceutical companies, eager to explore this new, uncultivated market. (Igor T, the RuMSS president in 2016, personal communication, 2017).*

Igor's reference to the invisible work encompasses activities such as collecting, organising, and systematising regional practices, training and learning initiatives, and the establishment and maintenance of alliances. These unseen yet foundational processes contributed to the visible "wholeness" of the RuMSS. The subsequent visible practices, such as fundraising or engagement with the media, were contingent upon the invisible internal processes of strategically identifying and nurturing practices aligned with the ‘dominant rationality’ of the new political regime (de Certeau, 1990). In essence, the visibility of these practices was dictated by their alignment with scientific and administrative institutions, integrating the RuMSS's visible procedures into the new healthcare landscape and establishing it as one of the most influential patient organisations in Russia—an expert in policy advice, medical goods and services assessment, and disease management.

Yan Vlasov particularly emphasises the credibility of the RuMSS claims, attributing it to the foundation in sociological research and the adept use of sociological devices such as surveys, questionnaires, and publications (see similar work in [Moreira et al. \(2014\)](#)):

*We are very meticulous in our sociological research: the field workers comprise regional patient members, and experts are drawn from Social Mechanics, the medical community, etc. We also collaborate with MS care centres to construct a “patient chart” detailing needs and demands - medical, social, rehabilitative. All our research results are published in medical journals, on the website, and in reports to the ministries – the same results presented in different ‘languages’ (personal communication, 2017).*

The strategic operations of the RuMSS are systematically documented in methodological materials, constituting an additional layer of visibility within the realm of invisible work. For instance, one methodological document classifies various activities - such as engaging partners, conducting research, and formulating solutions - in accordance with shifts in dominant governmental strategies over the years: “in 2001, MS is a medico-scientific problem; in 2004 – medico-social; in 2007 (the year before elections) - socio-political; and in 2010 – a socio-economic problem” (The Experience of the All-Russian MS Society, 2011). Besides these methodological materials, the strategically visible work of the RuMSS is acknowledged as “best practices” during the annual All-Russian Patient Congress, regional MS society training sessions, and in various publications, including website pages, academic articles (Vlasov et al., 2017), press releases, open letters to the government, and even Yan's habilitation thesis (Vlasov, 2006). The interplay of visible and invisible work within the RuMSS is thus multidimensional and multidirectional, with layers of (in)visibility enveloping work like onion leaves, revealing different depths to different actors and observers.

Heterogeneous work initially developed under the treatment access strategy was subsequently transferred to other strategic streams aimed at ‘making patients' voices heard’ (Holavins and Zvonareva, 2022), such as policy mediation, healthcare services assessment, or medico-social expertise. This work, invisibly executed on a daily basis (reaching out, explicitly stating practices or concerns in questionnaires), becomes visible in strategically meaningful situations and in a format consistent with the ‘dominant rationality’ of the healthcare system (de Certeau, 1990). For instance, instilling methodological rigour and “best practices” to harmonize local practices into collectively shared, traceable, and generalizable work or generating patient charts and

academic publications to ‘base in evidence’ (Rabeharisoa et al., 2014) patient needs. By validating the rationality of specific RuMSS practices - such as patient training, policy advice, or sociological understanding of MS - the RuMSS leaders establish the legitimacy of their expertise among governmental leaders, the media, other patient organisations, or regional MS groups, positioning the RuMSS as a cohesive entity among other stakeholders. Similar to how visibility operates in layers contingent on the intended audience, the viability of strategic work within the RuMSS is maintained by numerous layers of invisible tactics. This can be exemplified through the illustration of the *Seven Nosologies* program.

### **5.2. Background tactics: layers of invisibility in support of (and escape from) strategic work.**

*The Seven Nosologies* is a state-subsidised treatment provision program that covers the seven most expensive treatments for chronic illnesses from the state budget (including haemophilia and multiple sclerosis). Yan Vlasov asserts that the establishment of the *Seven Nosologies* was not only the outcome of meticulous strategic work but also an improvised “situation” made possible only in that historico-political moment and solely due to the previously built knowledge and relations:

*[We were] supported by Leonid Mikhailovich Roshal - the chair of the National Medical Chamber. Back then, I think, he was Putin’s counsellor for the healthcare sector. (...) we went to the Duma and wrote a letter to the president. Finally, the four loudest organisations (the RuMSS and Haemophilia Society included) were invited to the Duma [a legislative body] with a question “What do you want”. We wanted free treatment provision. And, moreover, we knew how to achieve it. We demonstrated lists with all the patients and the calculation of the process. We knew how to negotiate with the pharmaceuticals for bringing the prices down in bulk purchases ... we knew a lot – and we knew how to make it work (...). The Duma has brought our demand to Medvedev. And by the evening that same day, there was announced the start of the program Seven Nosologies. We could not understand how it was even possible legally - the budget of the Russian Federation has just been adjusted by one line - “Program Seven Nosologies”. (Fieldnotes, November 2019).*

The first round of the *Seven Nosologies* took place from 2008 to 2010. During this period, POs (particularly, the RUMSS and Haemophilia Society) organised their work around the strategy of mediating between medical professionals, pharmaceutical companies, and state institutions. They negotiated with pharmaceutical companies for favourable prices, simultaneously presenting research results that highlighted the advantages of bulk sales to the state. Additionally, they negotiated with state leadership for involvement in decision-making processes, underscoring that this would enhance their popularity among the constituency. Towards the end of 2009, the mutual interest in extending the duration of the *Seven Nosologies*, within the context of consolidation of the authoritarian regime, led to the establishment of the Russian Union of Patients (RUP) – a ‘Russian doll’ structure comprised of over 24 federal organisations and their 180 regional chapters.

Yan explains that the *Seven Nosologies* came as a surprise not only to the patient movement but also to state leaders. Most of the time, RuMSS activists “keep the work quiet” (and they advise others in the patient activism sphere to do the same) to avoid attracting “unnecessary interest”. It is in specific situations, sometimes planned (such as a training event) and sometimes unplanned (like an invitation to the Duma), that the work becomes visible, adding credibility to ‘abstract indicators’ (Star and Strauss, 1999) such as the number of MS patients in need of DMTs or positioning MS as a “socio-economic problem”. Strategic visible work thus does not contradict or undermine the principle of “keeping work quiet,” even if it involves the same practices. Instead, in line with Certeau's (1990) reflections, the dominant rationality prescribes specific courses of action for patient organisations (POs), and if the visible work of POs closely aligns with these prescriptions, there is potential for patients, organisational leadership, and even stakeholders to creatively navigate invisibly the spaces in between and establish new pathways.

What Yan describes above is not the sole layer of invisibility that supports the strategic work of the RuMSS. Following the logic of the ‘federation’ of numerous local organisations, the RuMSS and the RUP operate in a representative manner, meaning that the diverse concerns of patients are consolidated under the strategic lines of work and voiced by public leaders, primarily Yan, Igor, and Mikhail. Despite the predominant impact of MS on women, the public representation

of the RuMSS (mass media appearances, lobbying meetings, authorship of publications) is mostly male and carried out by individuals without MS. According to some women activists from the Moscow MSS, this disembodiment and abstraction of work supporting the RuMSS offer strategic advantages: in patriarchal Russian society, having men speaking for the group adds legitimacy and acceptability in the dominant regime, and *“facilitates our victories. Anyhow, within the organisation, everyone knows who really forms its core”* (personal communication, April 2017). Secondly, MS in Russia remains a ‘hidden illness’: many diagnosed individuals conceal their condition for fear of job loss or discrimination. Abstracting bodies with MS into “MS patients” somehow safeguards the personal lives of activists. Nevertheless, these ‘advantages’ come at a certain cost: locally situated patients-activists and their concerns, such as managing MS during menopause or pregnancy, are rendered invisible and excluded from public debates. Local MS activists are reduced to the status of ‘non-persons’ (Star and Strauss, 1999:15) in the strategic representation of the RuMSS's work. They emerge as repositories of skills, numbers in a statistical set, testimonials, ‘nature morte’, represented and embodied by a handful of leaders. Their work, from gathering data for RuMSS sociological research to navigating institutional complexities (Temina et al., 2023), or managing bodies with MS, is silenced and neglected on the ‘federal’ scale. Yet, it becomes visible and appreciated in the everyday ‘ruses’ and ‘tactics’ (de Certeau, 1990) of regional MS Societies. I will elaborate on this later in the article.

Commenting on his narrative about the *Seven Nosologies*, Yan Vlasov, a neurologist by training, emphasises that the essence of the PO's success in addressing patients' concerns lies in traceable and replicable “science-like” work. However, Yan points out that the limitation of replicable practices is that this work “works” only when it is performed with care. Activist work is carried out by individuals in specific moments; it is infused with emotions, intuitions, trust, charisma, and is *“very similar to the work of medical professionals: having medical knowledge is not enough to be a good doctor”* (personal communication, December 2019). According to Yan, this ‘background work’ (Star and Strauss, 1999: 15) cannot be explicated; it can only be cultivated through collective effort. The background work mentioned by Yan can be interpreted as the default expectation of care (Star and Strauss, 1999) within POs, divested of its previously mentioned “unsettling” (Murphy, 2015) and troubling properties. I will revisit this later, pausing

now at another aspect of Yan's narrative. The interplay of visible and invisible work yields results only in “favourable situations”, specific chronotopic arrangements, such as a meeting room in the Duma before the presidential elections of 2008. Sensitivity to these favourable openings is a part of very specific invisible work within the RuMSS, as I instantiate in the next section.

### **5.3. The (invisible) work of *composition*: how work co-emerges with time-spaces**

*It is May 26, 2017. We stand in front of Moscow City Hospital № 24, one of the five city hospitals hosting Inter-district Multiple Sclerosis (MS) Branches, serving as specialised MS care centres. Olga, Alexandre, and myself. Olga, serving as the president of the Moscow Multiple Sclerosis Society (Moscow MSS), has arranged this encounter. Alexandre, a social media manager for the Moscow city government, is known for his advocacy work in the youth movement for patient rights, including organising social media campaigns and MS-related events. Alexandre has a personal connection to MS as his mother has the condition, and his father holds a prominent position in the RuMSS.*

*We stand in the driveway in front of the closed grey hospital gates, operated remotely by an access-control officer situated in a booth to our left. The choice of this location and time was proposed by Olga in a previous email exchange, silently assented to and facilitated by a former RuMSS president in CC. Our meeting coincides with the break time of Olga and Alexandre's working session, which is dedicated to preparing for the upcoming official celebration of International MS Day. Despite expressing interest, my request to attend the working meeting was politely declined, with the explanation that “the hospital management prefers to keep it confidential”.*

*Standing outside in an awkward small circle, we exchange introductions. Olga offers apologies for the “inconvenient” meeting place, clarifying that this “confidential” working meeting pertains to the preparation for the celebration of International MS Day on May 31st. She explains that the event is being utilised by “the officials” to showcase the accessible environment of the MS ward during a scheduled press tour. This tour has been organised in response to numerous*

*patient claims and accessibility assessments conducted by members of the Moscow MSS, revealing the satisfaction of the need for adjustments to ramps, door orientations, corridor widths, and more.*

*In a sarcastic exchange between Alexander and Olga, I gather that the press tour is primarily tailored for the “first person” (a reference to the head of the Moscow Department of Healthcare). Essentially, it is a “performance” orchestrated by the hospital management for the “first person”. Notably, no MS patients, especially members of the Moscow MSS, have been invited to participate in the show. Furthermore, to ensure the tour proceeds smoothly, the hospital will be closed, and all appointments with doctors will be cancelled on the day of International MS Day.*

*(Olga): He [the first person] would arrive, walk through the wards, and everybody would look at him, like, “Here is our great master” (...). He has no interest in real people (...).*

*(Alexander): (...) Maybe he actually wants to talk to real people. Too bad he will find no real people there [laughing].*

*(Olga): If that’s his true desire, he can come and visit us in Butyrsky. I will gladly cut him a piece of cake [laughing].*

*Olga elaborates that the Moscow MSS is planning a “real” celebration on May 29th, known as the “Russian MS day”. This “real” celebration will be held at the Centre for Social Services located next to the Butyrsky metro station. She explains that it will be a serene and amicable gathering, attended by the core group of the Moscow MSS, comprising approximately 50 patients and their family members. Olga extends an invitation for me to participate in this “real” celebration, asserting that it would offer more valuable insights for my research compared to the official “places and faces.” She says that I will see what “our Ministry doesn't provide and doesn't consider important” – rehabilitation inventions and experts on living with MS - all shades of MS lives. (Fieldnotes).*

On May 26, 2017, during the break in the working meeting and standing outside Moscow City Hospital № 24, Olga and Alexandre engage in *composition work*. They put together strategic and

visible work, such as forming alliances with medical institutions or collaborating with the media, with the invisible yet vital practices that breathe life into the organisation of MS patients - celebrating, enjoying a cake, meeting, and sharing. They do this with careful consideration of time and space or *chronotope*. Their composition work is made visible only to me, and only after taking certain precautions, including obtaining confirmation from the former RuMSS president, who is also Olga's friend, that I am 'safe to meet with'. In this specific 'matrix of visible and invisible work' (Star and Strauss, 1999:15), in relation to me as a researcher, the strategic work is "kept confidential" while playful *ruses* and ephemeral escapes from strategic constraints (de Certeau, 1990) are brought to my attention.

The grey hospital gate and the pause in the working meeting create a divide, a limbo zone where, on one side of the gate, what is visible is the strategic preparation of a press tour. Here, MS patients are being represented by official stories and tangible results (demonstrating an accessible environment), avoiding jeopardising the "cleanness" of the argument through their embodied presence. Outside the hospital gate, however, strategic work transforms into a "performance", something perceived as 'not real'. Here, what is visible and valued is the mundane and playful work and the embodied communal celebration. The visible and invisible, strategies and tactics co-exist in *composition*, embedded in specific time-spaces or chronotopes - the official chronotope of the International MS Day and the "real" chronotope of the Russian MS Day.

The co-emergence of visible and invisible work with chronotopes facilitates the search for something common while caring for the heterogeneity of its composite parts. Olga and Alexandre collectively share what to make visible or invisible in each particular setting: where/when to "perform" credibility, where/when to laugh, where/when to eat a cake. They know, from doing continuous composition work, that the chronotope of the International MS Day embeds patterns of work and emotional charge different from the chronotope of the Russian MS Day. In one case, the work should be clean, official, aligned with federal strategies and methodologies. In another, the work is improvised and playful. Playfulness is a significant pattern of invisible work observed during the meeting next to the hospital (Olga and Alexandre's sarcastic dialogue) and during the celebration in the Butyrsky centre. It aids in escaping the

rationality of patient activism and maintaining the heterogeneity of the collective “we” without opposition.

Standing near the City Hospital, Olga and Alexandre compose invisible practices, personas, timespaces, body reactions, and concerns which “will never make a whole, but at best a fragile, revisable, and diverse composite material” (Latour, 2010: 474.). Their invisible composition work not only allows for the coexistence of heterogeneous RuMSS activities as something common without opposition but also illustrates the practical aspect of ‘background care’, as highlighted in Yan's story of the Seven Nosologies. I will empiricise this point more deeply in the next section.

#### **5.4. Achieving local efficacy: composition work as modality of care in patient organisations**

*It is July 28, 2017. The 23 of us are standing outside the Centre for Palliative Care in the north-western part of Moscow, with wheelchairs, canes, strollers, and picnic materials. The Centre is a former City Hospital №11 where the Moscow MS Society had its office until 2014 when the hospital was reorganised due to healthcare optimisation reforms. The Center (rather, its parking lot) is still a common meeting place for many outdoor activities of the Moscow MSS.*

*We are waiting for the bus with accessible conditions rented from the All-Russian Disability Society within the 3 months of advance notice. This bus will take us to Prokhorovo - private stables 40 min south of Moscow - where we will ride horses and enjoy the countryside for 700 rubles each (about 12 dollars at the time). Our contributions are collected by Yulia, the organiser of this trip and an MS patient for more than 20 years. A part of them will cover the bus services, and the rest will be given in cash to Eugen, a middle-aged MS patient owning the stables .... (...)*

*Eugen says, “We are trying to open a hippotherapy centre for MSnicks here [MS (Multiple Sclerosis) + linguistic ending that signifies a sense of identification with something/belonging to a certain group]. I have been ill for a long time - I know very well that horses help to endure. We have been organising these trips for 5 years already. But you see – we have no infrastructure.*

*Nobody wants to invest in hippotherapy - it's not a pill. Pharmacology is a scary machine, and we cannot go against it” – Eugen says this last sentence very slowly, articulating each word. Then he mounts the nearby horse in one jump and yells in a perky tone to Alexandra, the vice-president of the Moscow MSS and MS patient: “I will show you something - this shall not be documented or they will revoke my disability rights”. Putting the horse into a free walk, he stands at full height on the horse's croup and laughs, balancing along the horse's movement. “Eugen, next time I go to the Bureau of Medico-Social Expertise, I will personally write a complaint revealing that you receive disability allocations for nothing. Do not get on my nerves,” - Alexandra yells back, half amused-half annoyed.*

*A young woman announces loudly, “Who needs to exchange the DMTs - come sign in!” She explains to me, “Typically, neurologists prescribe a DMT option in an individualized manner. According to the Seven Nosologies, all DMT prescriptions are free of charge. The problem is that not all the options appear in stock at the same time: sometimes, we have one DMT option in abundance and others are not available. And, at the same time, we should show that all the DMTs are being used by patients; otherwise, the state will reduce the number of DMT purchases. So, what we do is that the neurologists prescribe all the DMTs available, patients take them, and then exchange them for other DMT options once they appear in stock. We facilitate this: we keep the lists and survey that exchanges are done in strict accordance with the neurologists' recommendations.” (Fieldnotes).*

The Prokhorovo event sheds light on the diverse ways of caring within a patient organisation: caring for the memories of the RuMSS's previous status, ensuring bus accessibility, tending to the well-being of the horses, looking out for Eugen's safety, and safeguarding the Seven Nosologies. In Prokhorovo, the approaches to care differ from the taken-for-granted expectations presented in Yan's story. Instead, they align with feminist accounts of non-innocent and "unsettling" care (Murphy, 2015), which make visible inequalities and neglects in dominant systems. These mundane and often overlooked care gestures were and will not be visible to the governmental officials or the RuMSS leadership. Only those who were part of the Moscow MSS community of practice on that specific day could see and appreciate these manifestations of care - only those who understand how to be *MSniks* rather than just *MS patients*.

The term "MSnik" serves as a reminder that living with MS is an active practice, and being a patient in a community of practice is a form of work and activism, even if it is as simple as answering questionnaires. People with MS *do things* and share their "know-hows" (Pols, 2014: 83). For instance, Eugen, who is also an MSnik, participates in hippotherapy himself and organises this experience for his "colleagues," as he calls other Moscow MSS members. The work of MSniks is driven by concerns of care, which may not be profitable enough to invest in, yet simultaneously not traceable enough to be surveyed, controlled, or punished. Aligning with Temina et al. (2023) description of *adjusting work* done by Russian patients to access treatments, the invisible work of MSniks subtly addresses the limitations of the RuMSS's strategic victories without overtly opposing them (as seen in the medication exchange).

In the chronotope of the Prokhorovo stables, explicit categories that organise federal work, such as institutional affiliation, rehabilitation, disability status, or free DMT prescriptions, are being recomposed to enhance their effectiveness for members of the Moscow MSS in this specific moment. For instance, Alexandra's playful warning about revoking Eugen's disability status or the lack of infrastructure in the Prokhorovo stables challenge conventional notions of disability, medico-social expertise, and space accessibility. Despite the bio-toilets in Prokhorovo being inaccessible to wheelchairs and requiring MSniks with limited mobility to rely on their "colleagues" for assistance, the stables were more 'accessible' in practice than hospital corridors on other occasions (as discussed in section 5.3.).

The practices embedded in the Prokhorovo chronotope, such as organising a trip, horse riding, and exchanging DMTs, repair the invisibilities and neglects of the 'federal' RuMSS strategies. In this context, things, resources, and categories are (re)composed by the Moscow MSS activists to become 'locally effective' (de Certeau, 1990). This kind of efficiency is closely linked to care. It does not oppose or jeopardise 'federal work'. Instead, it involves transforming federal work into something more suitable for a given situation, more valuable in a specific time-space, and thus escaping the 'imposed rationality' (de Certeau, 1990) of patient activism (as seen in building alliances to rent a bus).

## 6. Conclusion

Patient organisations play a significant role in the transformations of health systems (Barbot, 2002; Epstein, 1996; Landzelius and Dumit; Rabeharisoa et al., 2014). While ample research attention has been given to POs' political action, expertise reclamation, and epistemic work, less attention has been devoted to the invisible work (Star and Strauss, 1999) that maintains patient activism. This article moves in this direction, analysing the situated articulation of visible activist work, such as the use of social science devices (Moreira et al., 2014), with the invisible 'tactics' (de Certeau, 1990; Star and Strauss, 1999) that make activism possible (meeting, eating, hiding, exchanging). Grounded in the observations of work with the Russian Multiple Sclerosis Society, I underscore the invisible *composition work* which maintains patient organisations, both their 'togetherness' and their heterogeneity and multiplicity.

'*Composition*' here refers to the continuous work of "building a common world" with care for its heterogeneity and without necessarily reaching a result (Latour, 2010). It points to collectively shared, embodied, and situated articulation of visible and invisible work, strategies and tactics, which are 'just in time' and 'just in place' to repair the damages of (in)visibilities. Strategic work, for example, is rendered visible on specific occasions, such as patients' congresses, official institutions, and lobby meetings, allowing reaching a certain legitimacy and 'rationality' within existing power structures (de Certeau, 1990). The "hidden and exiled" (Star and Strauss, 1999: 26), yet playful and creative invisible practices and tactics, meanwhile, challenge existing power structures (de Certeau, 1990) without opposing them. They become visible when patients get together in communities of local practice; their invisibility for those outside the community of practice helps achieve local efficacy and escape surveillance and control. Time-space arrangements or *chronotopes* have an important role in composition, embedding shared patterns of work and thus facilitating the search for a 'common'. Knowing when/where and how to render work visible or invisible is itself background work (Star and Strauss, 1999) that requires trust, intuition, and playfulness.

Bringing attention to composition work in research on patient organisations may have three main theoretical implications. The first is that of the 'ecology' (Star and Strauss, 1999) of visible and invisible work that makes possible and maintains patient activism. The second is that time-spaces

or chronotopes are actors in the communities of practice to Star's (1991), prompting articulation across multiple actors and things. Lastly, doing *composition work* – continuous negotiation of visibility and invisibility in activist work, without an expectation of a particular result – unavoidably involves care, in a sense that the latter has been conceptualised in feminist STS scholarship (Murphy, 2015; Puig de la Bellacasa, 2012, for example). It means accepting that care for some practices may silence some others but being willing “to work through discomfort, worry, anger, pain, disconnection, and living in non-alignment” (Murphy, 2015:731). It refers to the emancipatory promise of invisible care, reminding that “marginality is a source not only of monstrosity and impurity, but of a power that at once resists violence and encompasses heterogeneity”. (Star, 1991: 30).

### **Acknowledgements**

I would like to express my gratitude to my dissertation supervisors, Sonja Jerak-Zuiderent and Isabelle Ville. Their analytical sensitivity and more-than-academic guidance made the project underlying the article possible. I would like to additionally thank Sonja Jerak-Zuiderent for opening the door of feminist STS and care studies for me. I want to thank my thesis jury – Madeleine Akrich, Patrice Bourdelais, Joseph Dumit, Klasien Hortsman, and Emilia Sanabria for agreeing to think along and contribute a critical regard on the dissertation text. I am also infinitely grateful for the collaborative circle of the Russian Multiple Sclerosis Society and the Moscow MS Society, for their friendship which has been developing and intensifying over many years. I am thankful for the detailed and precious revisions provided by the anonymous reviewers, including the two reviews received during submission to another journal. Finally, I would like to express my gratitude to the Erasmus+ ‘Phoenix’ program which provided funding for my PhD study and to the Institutional Review Board of the Inserm (IRB00003888, IORG0003254, FWA00005831) which helped improve ethical considerations behind the study (opinion number 17–367).

### References

- Agha, A. (2005) Voice, footing, enregisterment. *Journal of Linguistic Anthropology* 15 (1): 38–59. doi:10.1525/jlin.2005.15.1.38.
- Agha, A. (2015) Chronotopic formulations and kinship behaviors in social history. *Anthropological Quarterly* 88 (2): 401–415.
- Akrich, M., Leane, M., Roberts, C. and Nunes, J. A. (2014) Practising childbirth activism: A politics of evidence. *BioSocieties* 9 (2): 129-152. doi: <https://doi.org/10.1057/biosoc.2014.5>.
- Bakhtin, M. M. (1981) *The Dialogic Imagination: Four Essays* by M. M. Bakhtin. Austin, TX: University of Texas Press.
- Barbot, J. (2002) *Les Malades en Mouvements. La Médecine et la Science à L'épreuve du Sida*. Paris: Balland.
- Barbot, J. (2006) How to build an “active” patient? The work of AIDS associations in France. *Social Science and Medicine* 62(3): 538–551. doi: <http://doi.org/10.1016/j.socscimed.2005.06.025>
- Callon, M. and Rabearisoa, V. (2008) The Growing Engagement of Emergent Concerned Groups in Political and Economic Life: Lessons from the French Association of Neuromuscular Disease Patients. *Science, Technology, & Human Values* 33(2): 230–261. <https://doi.org/10.1177/0162243907311264>
- Charmaz K. (1990). 'Discovering' chronic illness: using grounded theory. *Social science & medicine*, 30(11), 1161–1172. [https://doi.org/10.1016/0277-9536\(90\)90256-r](https://doi.org/10.1016/0277-9536(90)90256-r)
- Clarke, A. E. (2003) *Situational Analyses: Grounded Theory Mapping After the Postmodern Turn*. *Symbolic Interaction* 26(4): 553–576. doi: <https://doi.org/10.1525/si.2003.26.4.553>
- Clarke A E & Star S L (2008) *The Social Worlds Framework: A Theory/ Methods Package*. In: Hackett E J, Amsterdamska O, Lynch M, & Wajcman J, *The Handbook of Science and Technology Studies*. Cambridge, MA: The MIT Press, 128-153. doi: <http://doi.org/10.1007/s13398-014-0173-7.2>

- De Certeau, M. (1990). *L'invention du quotidien, I : Arts de faire*. Paris : Gallimard.
- Dodier, N. and Barbot, J. (2008) Autonomy and objectivity as political vectors in the medical world: Twenty years of public controversy about AIDS treatments in France. *Science in Context* 21 (3): 403-434. doi: 10.1017/S0269889708001841.
- Endaltseva, A. (2020). Communication and health knowledge production in contemporary Russia: from institutional structures to intuitive ecosystems.
- Endaltseva, A., Bachurina, N., & Mordvinova, M. (2021). Cocreating in the Wonderland: Communication and Patient-Oriented Healthcare in Russia.
- Edwards, C., Howlett, E., Akrich, M; and Rabearisoa, V. (2014) attention deficit hyperactivity disorder in France and Ireland: Parents' groups' scientific and political framing of an unsettled condition. *BioSocieties* 9(2): 153–172. <http://doi.org/10.1057/biosoc.2014.3>.
- Epstein, S. (1996) *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley, Los Angeles, London: University of California Press.
- Epstein, S. (2008) Patient groups and health movements. In: E.J. Hackett, O. Amsterdamska, M. Lynch, and J. Wajcman (eds.) *The Handbook of Science and Technology Studies*. Cambridge, MA: MIT Press, pp. 499e539.
- Epstein, S. (2016) The politics of health mobilization in the United States: The promise and pitfalls of “disease constituencies”. *Social Science & Medicine* 165: 246–254. <https://doi.org/10.1016/j.socscimed.2016.01.048>.
- Holavins, A. and Zvonareva, O. (2022) The Expertise Of Patient Organisations: Making Patients' Voices Heard. *The Journal of Social Policy Studies/Zhurnal Issledovaniy Sotsial'noy Politiki* 20(2): 335-346. <https://doi.org/10.17323/727-0634-2022-20-2-335-346>
- Landzelius, K. and Dumit, J. (Eds.) Patient organization movements (special issue). *Social Science and Medicine* 62 (3): 529-792.
- Latour, B. (2010) An Attempt at a ‘Compositionist Manifesto’. *New Literary History* 41 (3): 471–90.
- Litvyak K L, Plygunov K A & Katasonov A V (2015) Коррупция в России: История и современность. *Historical and social education ideas* 7(4): 35-39.[in Russian] Retrieved

- from <https://cyberleninka.ru/article/n/korrupsiya-v-rossii-istoriya-i-sovremennost-2>
- Mazanderani, F., Kelly, J. and Ducey, A. (2018) From embodied risk to embodying hope: Therapeutic experimentation and experiential information sharing in a contested intervention for Multiple Sclerosis. *BioSocieties* 13(1): 232–254. <https://doi.org/10.1057/s41292-017-0066-z>.
- Mol, A. (2002) *The Body Multiple. An Ontology of Medical Practice*. Durham, NC: Duke University Press.
- Moreira, T. (2012) Health Care Standards and the Politics of Singularities: Shifting In and Out of Context. *Science, Technology, & Human Values* 37(4): 307–331. <https://doi.org/10.1177/0162243911414921>.
- Moreira, T., O’donovan, O. and Howlett, E. (2014) Assembling dementia care: Patient organisations and social research. *BioSocieties* 9(2): 173–193. doi:10.1057/biosoc.2014.6.
- Murphy M (2015) Unsettling care: Troubling transnational itineraries of care in feminist health practices. *Social Studies of Science* 45(5): 717–737.
- Nicolson, M. and Lewis, G.W. (2002) The early history of the Multiple Sclerosis Society of Great Britain and Northern Ireland: A socio-historical study of lay/practitioner interaction in the context of a medical charity. *Medical History* 46(2): 141–174. <https://doi.org/10.1017/S0025727300069064>.
- Pols, J. (2014) Knowing Patients: Turning Patient Knowledge into Science. *Science Technology and Human Values* 39(1): 73–97. doi: <http://doi.org/10.1177/0162243913504306>
- Puig de la Bellacasa M (2012) ‘Nothing comes without its world’: Thinking with care. *The Sociological Review* 60: 197–216.
- Rabeharisoa, V. (2003) The struggle against neuromuscular diseases in France and the emergence of the “partnership model” of patient organization. *Social Science & Medicine* 57(11): 2127–2136. [https://doi.org/10.1016/S0277-9536\(03\)00084-4](https://doi.org/10.1016/S0277-9536(03)00084-4).
- Rabeharisoa, V. (2006). From representation to mediation : The shaping of collective mobilization on muscular dystrophy in France. *Social Science & Medicine*, 62(3), 564-576. <https://doi.org/10.1016/j.socscimed.2005.06.036>.

- Rabeharisoa, V., Moreira, T. and Akrich, M. (2014) Evidence-based activism: Patients', users' and activists' groups in knowledge society. *BioSocieties* 9(2): 111–128. doi:10.1057/biosoc.2014.2.
- Star, S. L. (1991) Power, technology and the phenomenology of conventions: On being allergic to onions. In J. Law (ed.) *A Sociology of Monsters: Essays on Power, Technology and Domination*. London: Routledge, pp.26-56.
- Star, S. L. and Strauss, A. L. (1999) Layers of silence, arenas of voice: The ecology of visible and invisible work. *Computer Supported Cooperative Work* 8: 9–30. doi: <https://doi.org/10.1023/A:1008651105359>.
- Temina, O., Zvonareva, O., & Horstman, K. (2023). Patients' work and fluid trajectories : Access to medicines for oncological and rare diseases in Russia. *Social Science & Medicine*, 317, 115613. <https://doi.org/10.1016/j.socscimed.2022.115613>
- Valyukh, M. V., Makshakov, G. S. and Luchkevich, V. S. (Eds.). (2018) MS risk factors and medico- organizational practices for the improvement of life quality for people with MS [translated from Russian]. Saint Petersburg: Nordmedizdat. Retrieved from: [http://www.patients.ru/media/407289/internet-versiya-sait\\_oooibrs.pdf](http://www.patients.ru/media/407289/internet-versiya-sait_oooibrs.pdf)
- Vlasov Y V (2006) Научное обоснование организации системы медико-социальной помощи больным рассеянным склерозом на современном этапе (Dissertation Professor of Medical Sciences 14.00.33). Public Health and Healthcare: St.Petersburg, Russia.
- Vlasov Y V, Churakov M V, Berkovich R & Sineok E V (2017) Оценка пациентами эффективности терапии рассеянного склероза. *Практическая медицина* 1 (1 (102)): 78- 87.
- Zvonareva, O. and Horstman, K. (2018) Introduction. Dealing with multiple uncertainties in post-Soviet health, technologies, and politics. In: O. Zvonareva, E. Popova and K. Horstman (eds.) *Health, Technologies, and Politics in Post-Soviet Settings: Navigating Uncertainties*. Cham, Switzerland: Palgrave Macmillan, pp.1-35.