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*Academic Editors*

Olga Zvonareva (Maastricht University)

Claudia Egger (Utrecht University)

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# Ambivalence and Agonism of Public Participation in Contemporary Societies

Olga Zvonareva <sup>1</sup>  and Claudia Egher <sup>2</sup>

<sup>1</sup> Care and Public Health Research Institute, Maastricht University, The Netherlands

<sup>2</sup> Copernicus Institute for Sustainable Development, Utrecht University, The Netherlands

**Correspondence:** Olga Zvonareva ([o.zvonareva@maastrichtuniversity.nl](mailto:o.zvonareva@maastrichtuniversity.nl))

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## Abstract

In this editorial we introduce the thematic issue “Public Participation Amidst Hostility: When the Uninvited Shape Matters of Collective Concern.” The aim of this issue is twofold. First, it takes stock of various ways in which public participation can be hindered, directly and indirectly. Second, it investigates different kinds of participatory practices that emerge in situations of hostility towards public participation. Given that participation in such situations often involves working around formal procedures and public spaces and depends on remaining hidden, particular attention is paid to de-publicised participatory practices. Overall, the articles in this thematic issue show how hostilities co-develop with specific participatory practices that, in turn, attune to, navigate, and resist the particular (hostile) circumstances in which they arise. The articles draw attention to the ambivalence and, in some cases, agonistic quality of participatory processes in contemporary societies, where mutually constitutive relations between participation and hostilities towards it shape matters of collective concern, political agendas, and possible futures.

## Keywords

agonism; barriers to participation; democracy; exclusion; hostilities to participation; non-democracy; public engagement; public issues; public participation; uninvited participation

## 1. Introduction

Reports of “participatory turns” taking place in science governance, health care, urban development, and many other domains have been arriving steadily during the past decades (Bergmans et al., 2015; Delvenne & Macq, 2020; Siffels et al., 2021). The concept of public participation and those related to it, such as engagement and

co-creation, have gained credit in wide academic and political circles. Participatory initiatives have received support from regulators and funders, and the formats of such initiatives have proliferated. In the context of waning confidence in governmental decisions and controversies over technoscientific developments, public participation has often been put forward as a go-to solution for averting crises of democracy and expertise (Eyal, 2019; Krick, 2022; Nowotny, 2003).

Against this background, this thematic issue on public participation amidst hostility may look surprising. If the value and practice of participation are so well established, why do we need to examine hostilities towards it? However, this undertaking is justified and even urgent, considering two points. First, critical social science scholars, including scholars of science and technology studies (STS), have documented a wide range of practices and understandings that restrict and sometimes deter public participation, even where it is declared a priority (Krzywoszynska et al., 2018; Wehling, 2012; Williams et al., 2022). For example, members of the public may be welcome to deliberate on the implications of nanotechnologies that they find potentially problematic but unwelcome to question broader priorities for allocating research funding (Delgado et al., 2011). However, while critiques of the exclusionary effects of various participatory arrangements abound, less attention has been devoted to taking stock of the different ways in which participation is hindered. This thematic issue addresses this gap by investigating different kinds of hostilities towards public participation.

Second, most participation scholarship focuses on situations that can be characterised as democratic, where, at least in theory, publics are welcome to participate in political matters (De Loureiro et al., 2021). This focus is not due to the fact that outside such situations, publics are incapable of articulating and addressing matters of their concern. Scholars, however, have been conceptually limited in their ability to discern how participation in non-democratic situations happens because public participation tends to be conceptualised as hinging on making issues visible and debatable. Yet, participation in non-democratic situations may involve working around formal procedures and public spaces and depend on remaining hidden. Such participatory practices may never produce open contestations, in contrast to many cases analysed in the existing scholarship (e.g., the case of HIV/AIDS activists transforming biomedical research in the US by Epstein, 1996; see also Zilliox & Smith, 2018). Consequently, such practices are often excluded from academic accounts of participation. This thematic issue, in contrast, investigates different kinds of participatory practices, including de-publicised ones, that emerge in situations of hostility towards public participation.

It is these two lacunae that this thematic issue is positioned to address—to take stock of different ways in which participation can be hindered and to examine a broad range of more and less visible participatory practices that take place despite being unwelcome. To situate the articles comprising the issue in this editorial, we first discuss the operation of hostilities to participation and reflect on conceiving and noticing participatory practices in situations when participation is unwelcome. Further, we outline the thematic issue content, highlighting many intriguing ambiguities that the included articles bring to the fore. Not only can participation be welcome and unwelcome at the same time, but hostilities to participation may also occasionally open windows of opportunity for participatory practices instead of suppressing them. Furthermore, strategies to cope with hostilities to participation might have unintended effects throwing off the aims of participatory collectives. Striving to participate despite hostilities, actors employ practices that often uneasily entwine collaboration and contentiousness in relation to authorities; all the while, very similar participatory practices that blossom despite being unwelcome may have vastly different effects, some

supportive and others corrosive of democracy. Overall, the articles in this thematic issue show how hostilities co-develop with specific participatory practices that, in turn, attune to, navigate, and resist the particular (hostile) circumstances in which they arise. The articles draw attention to the ambivalence and, in some cases, agonistic quality of participatory processes in contemporary societies, where mutually constitutive relations between participation and hostilities towards it shape matters of collective concern, political agendas, and possible futures.

## 2. Understanding Hostilities to Participation

What we call here “hostilities” to public participation are diverse and often not deliberate; that is, there is nobody out there purposefully striving to hinder public participation. While some hostilities are directly geared towards obstructing participation, others emerge as indirect products of governance logics and entrenched ways of sensemaking. Using examples from the literature and the articles included in this thematic issue, below we briefly outline how “indirect” hostilities of the second kind operate and then touch upon more clear-cut hostilities that target participation directly.

### 2.1. Indirect Hostilities

Without denying participation outright, indirect hostilities operate to limit or circumscribe participation to particular preframed questions, controlled formats, or selected groups. Consequently, while the ideal of public participation in governing various spheres of life appears to be maintained, public contributions beyond a delineated territory become unwelcome. This is often the case in preframed participation events (Bogner, 2012; Irwin et al., 2013; Meyer, 2017; Tironi, 2015). One illustrative example of how this happens was provided by Braun and Schultz (2010). These authors described a Leipzig Youth Conference, a participatory event dedicated to the topic of genetics, organised in 2006 by the German Federal Ministry for Education and Research. It consisted of educating participants about the science of human genetics and then asking them to create films, posters, or other media products expressing their views on the regulation of genetic testing. Braun and Schultz (2010) highlighted that “at this event, the young participants were generally constructed...as a homogeneous social group,” members of which “supposedly do not hold controversial views” on the issue (p. 411). The media products prepared by the participants expressed very different positions on the matter at hand. However, since the purpose of the event was to create a final document that would present a single authentic view of “the young generation,” a debate among the group or an acknowledgement of conflicting demands was impossible. Braun and Schultz (2010) concluded that a “purified public” of such events is “carefully selected to exclude people who hold strong opinions, or who are engaged or politically organised. Or, if they do hold such views, they are prevented from presenting them” (p. 411).

There is no doubt that, in the example provided by Braun and Schultz (2010) and in many similar instances, participation in general is welcome; after all, the Youth Conference is a participatory event organised to facilitate the engagement of young people with genetics. At the same time, we can still discern indirectly exercised hostilities to participation, as only a limited range of contributions is welcome. With participation being circumscribed to consensus, everything that threatens its achievement is excluded, as is also highlighted by articles in this thematic issue (see, e.g., Morsello & Giardullo, 2025, about the uninvitation of pro-vaccine choice communities in Italy, and Värttö, 2025, on contestatory forms of public participation in the Covid-19 pandemic management in Finland).

Often especially unwelcome are potentially conflictual contributions by those who have already become concerned with the topic and formed specific commitments, individually or as members of organised groups. During the Leipzig Youth Conference and in other similar cases noted by STS scholars, such already engaged members of the public are presumed to be too entangled in their own interests, biased and, thus, incapable of deliberating for the common good (Welsh & Wynne, 2013). The organisers of the Youth Conference and other participatory events conducted in similarly highly scripted formats, such as citizen juries, tend to be much more eager to involve the so-called general public, consisting of those with no prior connections, allegiances, or formed views on the matters under consideration. Separating publics into open-minded ordinary citizens and variously termed vocal interest groups with already formed agendas allows to invite only the former, which “appear as more malleable constituencies, less inflexible and categorical” than the latter, as Lezaun and Soneryd (2007) argued. When participation is arranged via the “ordinary citizens only” route, it is easier not only to prevent confrontation, gloss over disagreements, and achieve consensus, but also to impose preframed agendas and avoid the consideration of alternatives while often legitimising already made decisions. Thus, we can notice how, in some situations, indirect hostilities to participation operate by justifying selective invitations for some and the uninvitations of others who are framed as having less right to participate, often due to being too actively concerned about a matter at hand.

There are many other ways in which indirect hostilities to participation operate. We do not intend to provide an exhaustive list, a task likely to be impossible because of the diversity of situation-specific configurations of hostilities to which the articles included in this thematic issue attest. Instead, let us mention one more example to illustrate the multiplicity and subtleness of the ways in which some participatory practices are made unwelcome. This example stems from our own research in the field of drug development, which has been undergoing a participatory turn in the last decade. Pharmaceutical industry players have started establishing and disseminating formats for patient participation to standardise emerging participatory arrangements that were nearly unheard of in this field until the 2010s. Our research (Egher & Zvonareva, 2024) demonstrates that the formats considered and increasingly put into practice tend to require that patients have in-depth knowledge of contemporary drug development processes, including the specificities of its different phases, industry practices, and even regulation. Patients without this knowledge are rarely considered suitable for participation. This preference for expert patients, as they are often called, is creating a narrow elite group of patients who have resources and opportunities to acquire the requisite knowledge and then repeatedly participate in drug development.

In this example, participation becomes circumscribed to the topics and questions selected by the organisers of participatory exercises, most often pharmaceutical companies, primarily through insisting that most patients, being “lay” persons, do not possess the knowledge that would allow them to productively join the table where decisions are being made. Our research highlighted that being closely familiar both with how drugs are being currently developed and the companies that undertake the development might render expert patients less likely to pose questions that are critical and/or go beyond the technicalities of drug development itself, such as questions of access, pricing, and daily usage. In this case, then, hostilities to participation operate through distinguishing a new small class of expert patients endowed with an in-depth knowledge of a kind closely aligned with dominant practices and organisational arrangements in contemporary drug development and denying the relevance of other kinds of knowledge that broader groups of patients possess.

Many articles in this thematic issue further attest to the prominence and diversity of indirect hostilities, including the article by Liu and Coveney (2025), where the authors delineate multiple indirect barriers to



participation of people with disabilities in Covid-19-related policymaking, including exclusion of people with disabilities from data collection on the impact of pandemic control measures.

## 2.2. Direct Hostilities

The indirect hostilities delineated above do not necessarily entail an intention and specific focus on hindering participation. In contrast, the hostilities briefly discussed below are explicitly directed at hindering participation. They boil down to the claim that there is no need or reason for publics to participate, irrespective of the knowledge they possess, the format of participation they adopt or the concerns they have. Today, in many situations, such an attitude would be surprising and widely unacceptable. However, in what we might call authoritarian situations, this is what publics effectively face. And it is such situations that produce direct hostilities, as delineated below.

What are authoritarian situations? Let us take a look at the two components of this term—authoritarianism and situations—to get a feeling for how direct hostilities to participation are produced. In our usage of the word authoritarianism, we rely primarily on political anthropology scholarship. While the exact definitions of authoritarianism offered by this scholarship diverge, they tend to share three elements: (a) a highly uneven distribution of power, which is (b) maintained by coercion, and (c) the use of coercion, also to keep publics (selectively) disengaged and demobilised (Davey & Koch, 2021; Stroup & Goode, 2023). Another complementary line of scholarship is the practice-oriented approach to understanding authoritarianism, which moves beyond locating authoritarianism analytically solely at the level of the state and proposes instead focusing on practices as patterns of action embedded in organised contexts (Glasius, 2018). Taken together, these lines of scholarship allow understanding of authoritarian situations as constituted by practices of coercion used to maintain an uneven distribution of power and tight control over (certain) publics to keep them demobilised. It is these characteristics of authoritarian situations that produce direct hostilities towards public participation. An example from one of the articles in this thematic issue attests to how this occurs in practice. Zvonareva (2025) describes a case of participation in politics by networks of antiwar and prowar volunteers in contemporary Russia. Their participation takes place in a context of stark power differentials and coercion: Volunteers find themselves with little to no means of influencing authorities, whereas the authorities have an arsenal of means at their disposal to crack down on the work of volunteers, including imprisonment for violating “war censorship laws” and subjecting to violence in places like police stations—an illegal but widely adopted practice. The threat of such means being used is selective. It is directed at those who do not support the war, with a view to demobilising them, whereas those who support it are largely given free rein for the time being.

The word “situations”—the second component of the term “authoritarian situations”—highlights that authoritarianism (as well as democracy) is not strictly bound to specific states and cannot be defined geographically. Critical social science scholars have long stressed the patchy and uneven character of authoritarianism and democracy, where pockets of exclusion and exception exist within democratic states and participatory openings may occur in otherwise oppressive circumstances (Chilvers & Kearnes, 2020; Czada, 2015; Jasanoff, 2005; Laurent, 2011). Therefore, it is unproductive to view authoritarianism as existing uniformly within the boundaries of one state and ceasing to exist within the boundaries of another. To account for the disparate and dynamic character of authoritarianism, we employ the word “situation,” as it is localising and open-ended, more so than other related terms, such as “setting” (Barry, 2012; Birkbak &

Papazu, 2022). Looking at authoritarian situations, rather than, say, authoritarian settings, foregrounds the occurrence of direct hostilities to participation in what is typically considered democracies. In this thematic issue, the article by Stoli et al. (2025) illustrates this point. It highlights how an international community of transgender activists has found a way to participate in politics through home-based production hormones in a situation where it might be too dangerous to pursue other, more overt forms of participation. In comparison to the previous example, the push to remain disengaged and demobilised for this community is not country-specific, while the sources of coercion to maintain an unequal distribution of power are much more widely dispersed. It can be said that the members of this community find themselves in an authoritarian situation, despite many of them living in long-established democracies.

The various direct and indirect hostilities to public participation considered above are not mutually exclusive, nor are they always sharply distinct. In any particular case, we might notice that participation is made unwelcome through a situation-specific combination of more or less direct ways. The articles in this thematic issue trace how these ways operate and interact with participatory practices and how exclusions as well as ingenious forms of participation and solidarities emerge through these interactions.

### 3. Noticing Participation

Having discussed hostilities to participation, in this section, we briefly consider participation itself. What kinds of practices can be thought of as participatory? In delineating an answer to this question, in this thematic issue we draw on STS scholarship, as it allows accounting for a wide diversity of ways in which publics articulate and address matters of collective concern.

The understandings of participation advanced by STS scholars tend to emphasise its co-produced and relational character. In doing so, they depart from viewing publics and the issues with which publics are concerned as firmly delineated and existing in a clearly defined manner prior to participatory practices. Instead of existing “out there” in a natural form, ready to be consulted on any topic deemed in need of societal input, publics come into being together with the issues of their concern through processes of articulating and addressing these issues (Amelung & Machado, 2019; Marres, 2005). Take, for instance, the issue of agricultural transitions. There are, among others, farmers concerned about losing their livelihoods due to the pressure to transition away from livestock farming; some citizens concerned about water scarcity, impending not least due to large-scale consumption of animal products; and industrialists concerned about losses to their businesses should industrial stock farming be required to change its environmentally taxing methods. The issue of agricultural transitions entangles all these diverse threats to different livelihoods and lays bare the incompatibility of the interests involved. In the process of formulating these threats, clarifying what is at stake, articulating the issue of agricultural transitions as a particular kind of issue (e.g., of intergenerational justice or food security), and taking it upon themselves to address it, collectives concerned form, grow and emerge as a public. To sum up this mutually constitutive dynamic, Marres (2005) famously formulated: “no issue, no public.” She also stressed that it is through articulating and dealing with issues that publics come to be involved in politics, oftentimes when existing communities and institutions are incapable or unwilling to take care of matters of their concern. The articles in this thematic issue look at very diverse kinds of publics, all of which can nonetheless be understood as publics by virtue of their involvement in articulating and addressing collective concerns over certain thorny issues.

Not surprisingly, the ways in which these publics go about articulating and addressing collective concerns or, in other words, about practising participation, are also highly diverse. Refraining from prescribing what participation is and should be in advance allows the authors in this thematic issue to go beyond much researched deliberative and explicit public participation formats and to notice its various uninvited, everyday, mundane, and material forms (Jansky & Langstrup, 2022; Nielsen & Langstrup, 2018; Weiner et al., 2023). The articles in this thematic issue investigate efforts to affect matters of collective concern made in diverse areas of life, including those traditionally defined as non-political, such as producing medicines (Stoli et al., 2025) and arranging childcare (Tietje, 2025). These efforts are also made through diverse means, including co-creating films (Loftus & Murphy, 2025) and building houses (Schikowitz, 2025). Nonetheless, we can understand them as participatory by thinking about public participation in relational and co-productionist terms that emphasise how publics, issues, and participatory formats are interrelated and emerge together. As Chilvers and Kearnes (2020, p. 350) put it, “far from being external pre-given categories, the subjects (publics), objects (issues), and models (political ontologies) of participation are actively co-constructed through the performance of collective participatory practices, both shaping and being shaped by wider social, political and technoscientific orders” (see also Felt & Fochler, 2010).

#### 4. Articles in This Thematic Issue

This thematic issue originated at the conference panel Unseen Participation: When the Uninvited Shape Matters of Collective Concern, which we convened during the EASST Conference in 2022. The contributions to this panel showcased diverse and intriguing participatory practices performed in the face of various arrangements that limited, hindered, or persecuted participation. During the discussions that followed, the term “hostilities” popped up as a shorthand for referring to such arrangements.

The original focus of the thematic issue idea, born out of the panel presentations and discussions, was on the creativity of practices collectives employ to still affect matters of their concern, even when they are not welcome to do so. An open call for contributions further broadened the range of such practices that went beyond talk-based formats explicitly designated as participatory and could be placed side by side in the thematic issue to highlight their ingenuity.

However, as the articles that are now published within this thematic issue were being developed, it became difficult to maintain this original focus. It seemed to assume a degree of stability and definitiveness of both participation and hostilities that did not align with the flow and ambiguity the full texts of the articles made noticeable. A writers’ workshop, during which authors and editors came together, made it clear that the focus needed to be reformulated, taking into account the fact that neither hostilities nor participatory practices can be held constant in analysis or presumed in advance to have specific political implications. Hence, the thematic issue turned to focus on how participatory practices and hostilities interact and co-develop, together shaping the ways in which matters of collective concern are articulated and addressed. Looked at from this angle, the articles in this thematic issue still make the ingenuity and creativity of participation amidst hostility visible but also foreground its ambivalence. Below, we delineate the articles and how their order in this thematic issue makes visible different kinds of ambivalences, from ambivalences of institutional attitudes towards participation to the ambivalent outcomes of mutual shaping of participation and hostilities to it in different situations.

The articles in this thematic issue, first, highlight how omnipresent the ambivalence of institutional attitudes towards participation is. Despite discursive support and even prioritisation of public participation, the latter is very often significantly limited in practice. In their article on efforts by a citizen initiative to reinvigorate an empty neglected park in a Dutch city, Knibbe et al. (2025) highlight subtle but consequential hindrances the initiative encountered despite participation being nearly a “gold standard” for city planning and development. For example, one such hindrance had to do with ideas about what the public is and, thus, who can participate. Through experimenting with temporary changes in the park, holding neighbourhood events, and maintaining the green space, the initiative had managed to attract residents whose engagement with the events and regular presence at the park promoted friendliness, connections between neighbours, and engagement in communal affairs. The municipality, however, did not recognise the support the initiative received locally and thought of it as a small group of people, distinct from and thus nonrepresentative of the rest of the neighbourhood, which had long been framed in reports and official communications as a problematic one, with low participation of its poor and low-educated residents. Instead, the officials preferred statistical demonstrations of citizens’ support collected via questionnaires, which supposedly made it possible to tap into what an “average citizen” thought. Thus, the local authorities were inclined to dismiss the proposals of the initiative, as it did not represent “the whole neighbourhood.” The authors highlight that the “old’ realist approach to neighborhood publics, thus, reproduced the stigmatized “antisocial” neighborhoods and cut off the attempts to develop new neighborhood publics in the process.”

The article by Liu and Coveney (2025) on attempts by the international disability movement to influence Covid-19-related policy also highlights the ambivalence of institutional attitudes towards participation and that exclusionary dynamics intensify during crises. While in many settings civil society actors generally faced difficulties when trying to contribute to pandemic response, persons with disabilities faced additional barriers, despite a wide consensus and international policy guidance on the necessity for organisations of persons with disabilities to participate in Covid-19 policy—and decision-making. For example, one such barrier was the lack of accessible formats of communication, such as providing sign language interpretation and easy-to-read and audio descriptions in government briefings and press conferences. As a result, the members of organisations of persons with disabilities often lacked access to relevant information and were thus hardly in a position to contribute to Covid-19 policy—and decision-making. Another example of a barrier the authors identified is the exclusion of people with disabilities from Covid-19-related data collection at the national and UN levels. The lack of statistical data on the impact of pandemic response measures specifically on people with disabilities limited these organisations’ abilities to contribute.

At the same time, some articles in this thematic issue show how hostilities to public participation are ambivalent in that they not only oppress but also may configure new participatory constellations. For example, in his article on self-organisation among residents of the struggling El Raval District in Barcelona, Tietje (2025) foregrounds the dual impact of the welfare state transformation in Spain. On the one hand, increasingly left to fend for themselves, the residents have seen how issues of concern become individualised and responsibility for dealing with these issues is shifted to them. On the other hand, this same shift of responsibility inspired collective responses in areas such as housing, security and care through which the residents contradict individualisation, establish something in common and create (temporary) local participation infrastructures that also serve as infrastructures of welfare provision. In their article on the participation of pro-vaccine choice communities in public health politics in Italy, Morsello and Giardullo (2025) also show how hostilities to participation may unexpectedly open participatory opportunities. These

communities were explicitly uninvited from decision-making processes concerning vaccination and public health. This uninvitation was constructed through the country's stringent vaccination policies, including sanction regimes for those who were unvaccinated. It was also constructed through the public discrediting of pro-vaccine choice communities in the media, frequently portraying them as ignorant conspiracy theorists. Yet, in doing so, the Italian media also enabled pro-vaccine choice communities to gain unprecedented visibility, leading to an increase in followers, and inadvertently included them in the public discourse on vaccination, thereby facilitating the spread of their messages and the garnering of support. The authors stress that "inclusion and exclusion, as well as participation and non-invitation, are often intricately intertwined processes."

The intertwining of participation and hostilities is also the focus of the article by Gardenier (2025), who highlights a different dynamic: participatory practices proceeding amidst hostilities reconfigure hostilities as well. In this article, Gardenier focuses on Dutch volunteer hackers who have been identifying and disclosing vulnerabilities in computer systems since the 1980s, thus playing a crucial role in cybersecurity governance. Initially, the Dutch government viewed the disclosure of vulnerabilities by hacking as illegal and criminalised it. In response, some hackers stopped hacking, but others continued searching for and disclosing vulnerabilities, creating arrangements such as secret collaborations with journalists to do so without risking a prison sentence. At the same time, they formed a community and gradually reshaped initially hostile institutions to legitimise their work. The author emphasises that the hostility encountered initially by volunteer hackers is an example of institutional mismatch that arises when emerging forms of citizen participation, such as ethical hacking, are not recognised as such: "While cybersecurity campaigns assume a lack of citizen engagement and aim to foster participation where it is allegedly absent, in reality, citizen participation does occur but is not always acknowledged by institutions." Moreover, amidst attempts to cope with hostilities, participatory practices themselves may have unexpected 'closing down' consequences, as Angelucci et al. (2025) show in their article on migrant communities' participation in integration policy-making and implementation in a small town in Italy. For more than 20 years, immigration has been among the most contentious issues in the town's political debate. This article highlights the importance of intermediary figures in such small locales capable of acting as bridges between migrant groups and institutions. Such bridging figures, the authors argue, are "crucial for facilitating the transition from an adverse to a more inclusive political environment, enhancing participation by specific migrant groups." However, the authors also highlight the ambivalence of such figures because reliance on them "can promote participation, but it may confine it to individual interactions rather than foster broader migrant engagement."

Thus, together, the articles in this thematic issue put to the fore the mutual shaping of participation and hostilities to it. This is a continuous, uncertain, and ambivalent process, as Schikowitz (2025) makes clear in her article on how self-managed collaborative housing (CoHo) groups engage in and with urban planning in Vienna. Her article is situated in an environment where citizen participation is formally prioritised and encouraged but indirectly hindered by governance logics, planning practices, and administrative procedures. Schikowitz highlights how, in this environment, CoHo groups simultaneously make their aims compatible with and challenge urban planning visions and strategies in order to realise their projects and intervene in urban planning. The author elaborates that, "not only is the City both hostile and open towards CoHo, but CoHo is simultaneously hostile and open towards the City, co-producing hostilities and forms of participation that are specific for the indirect and ambivalent Viennese participation culture." Importantly, this co-production of hostilities and participation forms may, as in the case of CoHo in Vienna, create

“conditions for an ongoing political struggle, where coalitions and interactions are possible but are also constantly re-negotiated,” or in other words, facilitate agonism. Schikowitz argues that such an agonistic ongoing struggle allowed housing to remain a political issue, rather than being reduced to a technical problem—a development that “caters to both activist and municipal stances and might help to delay neoliberal developments towards commodification and financialisation of housing.”

In his article on the participation of citizens in the Covid-19 pandemic management in Finland, Värttö (2025) argues, more generally, for the beneficence of agonism—seeing value in conflict as something essential for the quality and liveliness of democracy, rather than something to be eliminated through consensus. He shows how during the pandemic, in the context of a lack of critical voices in public arenas, citizens expressed their concerns through information campaigns, protests, and demonstrations. The author suggests that “contestatory forms of public participation allowed citizens to scrutinise and challenge public policies by bringing light to the injustices and inequalities they created.” Not idealising these forms—Värttö acknowledges the voluminous literature on the potentially negative sides of civil activism during the pandemic—the article suggests that forms of participation agonistic in relation to institutional actors can contribute to more effective and democratic crisis governance. One such form of participation amidst the climate crisis is scrutinised by Tilk et al. (2025) in their article on bodily climate activism. They highlight how activists are increasingly using their entire body for/in climate activism by, for instance, gluing or tying their bodies to objects, barricading driveways, and sitting on public squares. These bodily ways of addressing shared matters of concern have recently been subjected to hostilities, often labelled “radical” and “terrorist.” However, by tracing how, during climate actions and manifestations, an activist’s body becomes multiply related to other bodies, public spaces, materials objects, law enforcement, media, and climate governance and policy, rather than being a stable and autonomous figure, the authors argue for the legitimacy of bodily climate activism. Drawing on their analysis, they argue “that bodily climate activism is a valuable avenue for non-violent public participation because of its relational transformative collectivity,” which goes beyond just placing demands on the state.

Importantly, the agonism—forms of conflict supportive of the quality and liveliness of democratic politics—noted by several articles in this thematic issue is not something that is guaranteed to be produced through the mutual shaping of participation and hostilities to it. The articles that focus on participation amidst direct hostilities in explicitly authoritarian situations demonstrate that further antagonisation and reaching the stage of not having anything left in common are also real possibilities; the more so the more coercive the surrounding circumstances are. For example, the transgender DIY hormone producers in Stoli et al. (2025) work around public spaces, maintain their invisibility, and do not attempt to draw attention to the injustices they encounter or to contest formal institutions. By producing their own hormones to aid in their transition, they resist dominant meanings and arrangements and actively build alternatives, which qualifies their practices as participatory, but they do so in an autarkic, self-contained manner. This community appears to have given up on engaging with opposing points of view and building a world in common with those hostile to its members. Zvonareva (2025) also highlights the divisive potential of participation amidst hostilities in her article about grassroots volunteer initiatives that emerged all over Russia after February 2022 to assist Ukrainian refugees. Most of these initiatives emerged in an attempt to resist the imperative of supporting the aggression against Ukraine foisted on Russian citizens by the state. But there also exist collectives similarly dedicated to assisting people from Ukraine, whose assistance activities do not mount resistance to the war-waging authoritarian state, but aspire instead to extend the



reach of this very state. These two types of volunteer collectives neither cooperate nor engage in any public discussions, nor do they stage open contestations of their opposing viewpoints. The author argues that by acting as a public on the issue of their concern—the war—these collectives have been persistently assembling alternative and incompatible versions of the world.

Finally, some articles in this thematic issue foreground the roles of academics in the ambiguous mutual shaping of participation and hostilities to it. Specifically, Loftus and Murphy (2025) explore the co-creation of the short film *Ordinary Treasures: Objects From Home*, a film that emerges as a form of academic activism amidst the rise of populism and anti-immigrant rhetoric in Ireland. In the film, six refugee participants share their stories through objects, such as a bloodstained Nicaraguan flag or a Tibetan sound bowl from Ukraine, carried from homes they were forced to leave. The film is an intervention enacted not “through narratives of victimhood but through the presence of matter—how objects, bodies, and voices coalesce to produce a different sense of forcibly displaced experience.” The authors argue that *Ordinary Treasures* is an enactment of “thick solidarity”—“uneasy, fragmentary, yet deeply committed to unsettling the narratives that seek to confine and reduce forcibly displaced lives.”

With this thematic issue, we hope to draw attention to the diverse implications of mutual co-development of public participation and hostilities towards it, as briefly outlined above. Perhaps one fruitful line of discussion could concern the agonistic qualities of public participation in contemporary societies and the possibilities of decentring consensus and deliberation in discussing and organising participation.

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### About the Authors



**Olga Zvonareva** is an assistant professor at the Department of Health, Ethics and Society, Maastricht University, the Netherlands. Situated in the field of science and technology studies, her primary research line concerns relations between scientific knowledge, technologies, and politics. She is especially invested in studying instances of participation in situations when members of the public are discouraged from doing so.



**Claudia Egger** is a researcher at Copernicus Institute of Sustainable Development, Utrecht University, the Netherlands. In her work, Claudia brings together insights from science and technology studies, medical sociology, innovation studies, and philosophy to explore the social, cultural, and ethical dimensions of digital innovations and novel participatory practices in healthcare settings. She is also researching transitions to preventive health.

# Citizen Participation in Healthy City Making: An Analysis of Infrastructural Work in a Low-Income City Area

Mare Knibbe , Sanne Raap , and Klasien Horstman 

Faculty of Health Medicine and Lifesciences, Maastricht University, The Netherlands

**Correspondence:** Mare Knibbe ([m.knibbe@maastrichtuniversity.nl](mailto:m.knibbe@maastrichtuniversity.nl))

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## Abstract

Despite a strong participatory discourse on the healthy city movement, researchers and activists indicate that low-income groups and city areas often are excluded from participatory urban development and do not benefit from healthy city policies. To better understand the challenges that citizens who promote a healthy urban environment in low-income areas face, we analyzed the infrastructural work of a citizens' initiative. We focused on their building of a socio-material infrastructure in an empty park surrounded by neighborhoods the municipality and other organizations classified as problematic in multiple ways. The infrastructural work consisted of experiments to attract new publics; regular work to revive a neglected garden; and negotiations with the municipality about new trees, natural play elements, and other additions to the park. However, residents' work was thwarted by institutional control over the neighborhood public and by unreliable bureaucratic interactions that resulted in endless waiting, adaptations, and failures. In this setting, citizens adjusted their infrastructural work by establishing new alliances and engaging in “garden diplomacy” to maintain constructive relationships and a hopeful perspective. The work citizens do to make new local publics should be acknowledged. Moreover, institutional obduracy and bureaucratic ambiguities form a hostile environment for citizen participation. We characterize this hostile environment as shaped by a “residual realism” that reproduces problem neighborhoods. We end with our contribution to a co-constructionist approach to public participation.

## Keywords

citizen participation; inequality; infrastructural work; neighborhood health; neighborhood public; socio-material infrastructure; urban commons; urban green zones; urban health

## 1. Introduction

Healthy cities and neighborhoods require citizen participation, both in understanding what a healthy urban environment means and in exploring ways urban environments can be made healthier. At the 2017 International Conference on Urban Health in Coimbra, one speaker, dressed as a superhero in a harness, mask, and cape, introduced himself as *Peatónito* (pedestrian) from Mexico City. As it takes courage to cross a street in this city where public space is devoted to cars, he battled for a more walkable environment. He showed pictures of himself wrestling with cars to enable pedestrians and cyclists to cross the street. Citizen participation for healthy cities can be very visible and even heroic, as this example shows. However, not all citizen involvement takes this form. Indeed, citizen participation in improving urban environments is often more mundane and less easily discernible.

One major challenge of healthy city-making is developing and maintaining urban commons (Borch & Kornberger, 2015; Huron, 2015). Urban commoning practices enable resources such as water, public space, buildings, and air to be shared according to formal and informal rules and agreements; these practices are vital for regulating resource usage and for creating and maintaining common urban worlds where people with different backgrounds and societal positions can co-exist. Inspired by Latour's (2004) commentary on Ulrich Beck's peace terms, we understand attempts at sharing urban worlds as construction work. Latour (2004) observed that a shared "cosmos" is not a given starting point for politics but, rather, the result of construction work. People do not share a pre-given cosmos or universe but live in a "pluriverse." Making peace, therefore, is not a matter of finding the truth about reality by interpreting it but a matter of building shared worlds. Similarly, coming to share a neighborhood and its space requires construction work. Building an urban cosmos does not happen overnight: It requires significant daily work and interventions by citizens to facilitate shared urban life. Such citizen participation, however, faces the obduracy of a city's design. As Hommels (2005, p. 324) noted:

It is very difficult to alter a city's design: once in place, urban structures become fixed, obdurate. As a consequence, urban artifacts that are remnants of earlier planning decisions, the logic of which is no longer applicable, may prove to be annoying obstacles for those who aspire to bring about urban innovation.

In the context of this thematic issue about citizen participation amidst hostilities, we focus on participation as constructing a shared urban cosmos. The hostilities encountered in our study are best approached as obduracy and ambiguity. In the case we present, citizens did not face overt malice, antagonism, or aggression directed at citizen participation; however, their efforts to promote a healthy living environment were thwarted. In the discussion, we consider what this case tells us about the hostile environment that citizens' initiatives face, despite a strong participatory ideology in urban governance.

We contribute to discussions about making common urban worlds by addressing citizen participation through infrastructural work oriented toward making neighborhoods healthier and more habitable. We explore the context of this infrastructural work that was thwarted despite overt municipal support for citizen participation. In this article, we first introduce inequalities and participation in healthy city policies and explain how we approach citizen participation as infrastructural work. We then describe our collaborative methodology as developed in the University With the Neighborhood (UwtN), a collaboration in a low-income area in the medium-sized city of Maastricht (ca. 125,000 residents). We discuss how citizens

challenge and revise existing urban infrastructures, the obduracy and ambiguity they face, and how they adjust their socio-material infrastructural work in response. We end by discussing the implications of our analysis for understanding citizen participation in the construction of common urban worlds.

### **1.1. Citizen Participation and Inequalities in Healthy Cities**

With most of the world's population living in cities and continued urbanization expected, cities are increasingly seen as the locus of health promotion. The World Health Organization and healthy city networks assert cities are well positioned to fight noncommunicable diseases, such as cardiovascular diseases, diabetes, and cancer, and to promote mental health, social connectedness, and belonging (de Vries et al., 2016; Galea & Vlahov, 2005; Hartig et al., 2014; Partnership for Healthy Cities, 2024; Sisson, 2020). Initiatives to promote urban health often join forces with efforts to promote sustainable and biodiverse cities (The Global Goals, 2024). Urban struggles with the pollution of air, water, and soil, food deserts, heat stress, loneliness, marginalization, housing crises, and violence all impact citizens' health. However, these burdens of city life are not equally distributed across neighborhoods and income groups, which translates into health inequalities. Moreover, research about improvements in greening and sustainability shows that such efforts do not benefit all city residents. For example, Rigolon et al. (2021) concluded that, in Europe, green zones potentially have higher protective benefits for low-income groups compared to high-income groups; however, low-income neighborhoods have fewer green areas, and these are often of poorer quality than those found in high-income neighborhoods (Lee & Maheswaran, 2011; Rigolon, 2016). Parks and green zones of lower quality may be empty and unsafe areas that generate stress and fear.

In American and European cities, greening is often connected to market-driven urban redevelopments that push lower-income groups out of their neighborhoods or even cities (Anguelovski et al., 2022; Gould & Lewis, 2016). This impacts not only citizens' health but also their participation and voice in urban development. While urban planners experiment with participatory design methods, the opportunities for participation are often restricted to specific moments and procedures, excluding a variety of voices and forms of participation. In Amsterdam, this type of exclusion from decisions about neighborhood restructuring even led to a participation strike by citizens in the K-neighborhood, a high-rise neighborhood located in the Bijlmer, a low-income city area (Milikowski, 2020). During this strike, the K-neighborhood citizens refused to engage in participation trajectories organized by the municipality. To summarize, increased interest in citizen participation does not guarantee that citizens really have a say in urban development, especially in low-income settings. The restrictions on how, when, and where citizens can participate in shaping their living environments are examples of persistent hostilities toward participation. It is, however, because of the rise of a strong participation ideology that understanding such hostilities faced by citizens is difficult. We aimed to provide insights into these hostilities to imagine a more inclusive participatory development of healthy urban commons.

### **1.2. Citizen Participation as Infrastructural Work**

Our analysis of public participation in urban commoning was inspired by scholarship in science and technology studies on infrastructures and infrastructural work (Bowker & Star, 2000; Dantec & DiSalvo, 2013; Star & Ruhleder, 1996) and a discussion about relations between infrastructures and public participation (Baringhorst et al., 2019).

In *Sorting Things Out: Classification and Its Consequences*, Bowker and Star (2000) examined infrastructures in relation to the practice of classifying objects, humans, animals, and so on. The international classification of diseases (ICD), for example, enables information-sharing and standardization supported by infrastructures of libraries, laboratories, sanatoria, the World Wide Web, and research networks. While classifying is human, when infrastructures are built around specific classifications, they become social and material realities with a life of their own and resistant to change. As such, classifications can have detrimental effects on people's lives. For example, infrastructures for housing and public transport that were developed during Apartheid, based on classifications of race, perpetuated forms of apartheid even after apartheid policies were abolished. As such, classification systems and the infrastructures built around them should be questioned, opened up, and adjusted when they may be harmful.

While infrastructures behave like objects, such as railways or roads, Star and Ruhleder (1996) conceptualized infrastructures as processes. Infrastructures do not exist independently of their use; they enable everyday practices and, in turn, are shaped by them. Indeed, infrastructures shape the conventions in communities of practice—that is, groups of people that share a specific goal or concern and regularly use these infrastructures in their interactions—and vice versa: users' conventions shape infrastructures. Korn et al. (2019) outlined a similar perspective that does not treat infrastructures as stable entities but, instead, looks at “infrastructuring,” the continuous work of repair, maintenance, and use, to become a reliable basis for actions. The Paris subway, for example, was maintained and repaired through intense work on signs, standardizing the design of signs regarding directions and places at all stations, repairing damaged signs, and removing distractions (Denis & Pontille, 2014). Without regular maintenance of the signage system, confusion about places and directions would hinder the flow of people; likewise, commuters adjust their conventions to the requirements of public transport and its signage system and thereby shape how this infrastructure works.

Although infrastructures often fall into the background in our daily use of them, scholars point out that they increasingly become the objects of public contestation. Infrastructures are made public in the sense that they become objects of public scrutiny by concerned citizens (Baringhorst et al., 2019; Korn et al., 2019). Baringhorst et al. (2019) discussed relations between infrastructures and publics in an edited email conversation. They examined how new publics are formed in response to concerns about infrastructures and with the help of infrastructures. Citizens worry, for instance, about car-centered cities and self-driving cars and organize new publics of pedestrian activists. These publics that people form to resist existing or developing infrastructures are distinct from the public sphere of civil society that political theory usually foregrounds. Publics that contest specific infrastructures also engage in infrastructural work themselves by using and developing intersecting alternative infrastructures, such as walking routes. Marres (writing in Baringhorst et al., 2019), however, noted that a perspective on publics as those that are materially implicated also identifies other less activist members of publics. To illustrate, citizens are materially affected by air pollution, climate change, and the privatization of trains: They cannot refuse to breathe, and they still need to take delayed trains. While these are matters of widespread concern, such material publics lack the agency to resolve these issues. Marres referred to these publics as “intimately affected outsiders” (as cited in Baringhorst et al., 2019, p. 80) and argued that infrastructures can be seen as a materialization of interdependencies in our complex societies.

In this contribution, we combine this perspective on material publics (Baringhorst et al., 2019; Marres & Lezaun, 2011) with a perspective on social infrastructures (Klinenberg, 2018) to analyze work on



socio-material infrastructures as a way of constructing common urban worlds. Marres and Lezaun (2011) argued in an editorial about material participation that political theorizing should pay better attention to material practices and study them empirically as forms of citizen participation. Even the most mundane material interactions—for example, using or refusing to use water bottles—can be considered citizen participation. On this issue, Hawkins (2011) analyzed moral concerns about the case of water bottles—produced with oil and contributing to the global problem of plastic waste—and market responses, such as the promotion of water filters as a more responsible alternative. Such material objects become part of public contestation and concern, and handling or avoiding specific materials should be seen as enactments of citizenship (Marres & Lezaun, 2011). Baringhorst et al. (2019), in addition, suggested that many forms of citizen participation grow out of specific material practices, such as a repair café or urban gardens, through which citizens act upon their attachments and concerns. In these examples, citizens do not have readymade normative orientations as is often assumed in citizen participation research, but rather, they develop these orientations when they feel attached to a specific material infrastructure or place. Klinenberg (2018, p. 5) viewed such material settings as part of a social infrastructure, the gamut of interconnected “physical places and organizations that shape the way people interact.” As with other infrastructures, these socio-material infrastructures are formed by practices of use. For instance, socio-material infrastructures are shaped by informal classifications of places and people, such as youth hangouts, drug users’ places, “antisocials,” “scooter youth,” “foreigners,” “nutters,” and so on. These informal labels may be more or less directly linked to standards and formal categorizations of social status or disorder and, as such, affect how and where people interact with others.

In short, socio-material infrastructures can produce new publics, groups of citizens that are concerned about empty plots, loss of meeting places, or other impoverishments. The citizens’ initiative that is central in this contribution can be seen as such a concerned public. Against the background of theories on infrastructural work, citizen participation, and the making of publics, we study how citizens engage in infrastructural work to promote healthy and inclusive urban environments and what challenges they face when doing so.

## 2. A Participatory Methodology

From 2013 until now (2025), we have developed long-term research collaborations with low-income neighborhoods in Maastricht, a medium-sized city in the south of the Netherlands. This city struggles with transforming from an industrial to a service and knowledge economy, with the young university that was founded in 1976 as a new big employer. While the historical city center is advertised as “*Sjiek en Sjoen*,” a local dialect for chic and beautiful, our focus was on a residential area in Northwest Maastricht. The local public health institute, demographic statistics, and municipality characterize the neighborhoods in this area as having high rates of unemployment, high disease burdens, and low grades of citizen participation. This picture is produced within expertocratic knowledge infrastructures that monitor and promote neighborhood health in the Netherlands based on regular counting, measuring, and surveys involving little citizen participation (GGD Zuid-Limburg, 2022).

Based on initial years of participatory collaborations, we (authors of this article and residents of Maastricht Northwest) organized two citizen summits about urban health and well-being in 2014 and 2015, for which citizens were selected by lottery; the outcomes of the events shaped our research agenda. The central outcome was the idea that health and well-being were threatened by the fact that people did not know each

other anymore and that more public meeting places were required to address that problem. To address this need and to make structural space for new participatory pathways in making knowledge about the neighborhood, we initiated UwtN in 2017. UwtN is a collective for research, action, experiment, and engagement oriented toward making low-income neighborhoods more lively, habitable, and healthy. As part of the UwtN, researchers and research activities were present in the neighborhoods on a regular basis to enable collaborations with residents. In response to protests against professionals' stigmatizing assumption that residents only wanted to play bingo, we initiated a monthly philosophy café in 2017 that is still ongoing (Raap et al., 2023). With other residents, we initiated a working group, Social Green, with the aim of transforming a large boring park into a more attractive, lively social green (Knibbe & Horstman, 2022; Raap et al., 2022). We also organized a series of interactive, informal lectures in a neighborhood center to address themes that emerged during other neighborhood meetings, and we engaged with various existing neighborhood collectives and professional organizations (Raap et al., 2021, 2024). With neighborhood networks and the owner of a shopping mall, we established in a mall a public meeting place that is run by citizens. In all these collaborations, residents were engaged not as a source of data but as producers of knowledge through experiments, actions, and reflections (Raap et al., 2024).

The citizens' initiative Together Greener (TG) grew out of these UwtN collaborations and the Social Green working group. TG started in 2018 and experimented with small events to transform empty and "asocial green zones" into more lively and interesting public meeting places. To work on more permanent transformations of the neighborhood green zones and to be able to apply for funding, the group started a formal foundation, TG, with a board formed by three residents. Despite the foundation's formal status, the initiative preserved its informal and open character, enabling a variety of ways to participate. A small group of residents meets on a regular basis to discuss all ongoing projects and collaborations; however, a wider circle of residents joins in gardening and supporting events in the park.

To collect data (2013–2024), we used a participatory ethnographic approach with a mix of qualitative data collection methods, combining participant observations, walking interviews, individual and group in-depth interviews, film discussions in neighborhood centers, and neighborhood diaries, including texts, photos, and drawings. A more extensive explanation of specific data collection methods can be found in previous publications, and an overview is provided in Table 1 (Knibbe et al., 2016; Knibbe & Horstman, 2022; Raap et al., 2021, 2022, 2023 2024). The participatory approach meant that we collaborated with residents in all stages of our research, including discussing our analyses while in progress. Our role as researchers, on the other hand, also involved providing practical support, such as co-organizing park events, collecting garbage, and functioning as chair or scribe for meetings. This meant not only did we learn from residents, but we also experienced challenges to citizen participation firsthand, which contributed to the interpretation of hostilities to participation.

Data analysis proceeded through an iterative process of deductive and inductive coding. Deductive coding was shaped by sensitizing concepts connected to our different studies: restoration, enablement, public sociability, "commoning," collective action, placemaking, and formal-informal collaborations. In the inductive coding of previous studies, struggles with neglect, bureaucratic interactions, and dealing with stigma emerged as central themes (Knibbe & Horstman, 2022; Raap et al., 2022). For this article, we further analyzed the themes of stigma (stigmatizing classifications) and bureaucratic interactions guided by the concepts of infrastructural work and the theme of this thematic issue: citizen participation amidst hostilities.



**Table 1.** Overview of data collection methods.

Methods	Years	Data collection
Walking interviews with neighborhood residents	2017–2018	15 audio-recorded walking interviews conducted by researcher SR to gain insights into experiences with public neighborhood space, including green zones.
Participant observations of park events	Spring festival 2018 Yearly Summer Park Program 2018–2024 Willow-hut building during the 2020 lockdown Christmas gatherings in the park (in 2022 and 2023)	For example, pop-up tea gardens, theater workshops, children’s games, singer, campfires, giant bubble blowing, giveaway tables, reading corners, dancing, outdoor philosophy cafés, neighborhood camping, etc. Pictures and videos were captured by TG members and the authors/researchers. Field notes were written for a selection of these occasions interchangeably by the authors/researchers.
Participation in TG meetings to develop and discuss plans	2018–ongoing (every 3–4 weeks)	Researcher KH participates in all meetings, and researcher MK contributes to specific event-related meetings. Researcher KH keeps notes that are shared with TG members.
Park diary	Fall 2021–Spring 2022	With the help of a student, TG members collected citizens’ experiences in traveling park diaries, which were notebooks with a short introduction, including open questions about the park and an invitation to the reader to write and draw about their experiences in the park. An edited version of the park diary was distributed in neighborhoods and in the municipality.
Dog walker interviews	Fall 2022	A student conducted participant observations and informal conversations with dog walkers in a park. Recorded in field notes.
Park seminar	January 18, 2024	Residents and institutions involved in the park sat together to discuss past and future development of the grounds.
Meetings with the municipality	Meetings at the municipality, but also in the park and the neighborhood center	TG members, the municipality, and researchers KH and MK discussed plans to redesign the park and reflected on collaborations in the transformation of the park.
Weekly garden days Monthly garbage/cleaning days	2021–ongoing Every 4–6 weeks in Spring, Summer, and Fall	A garden team gathers every Tuesday and Saturday to maintain the park’s garden. They invite people walking in the garden to write something in a garden notebook, or they make notes themselves about the conversations they had. TG members and other residents gather each month on a Saturday to clean up litter and picnic in the park.
In-depth interview about citizen participation and hostility	Summer 2024	Researcher MK conducted an in-depth interview with a member of the garden team about experiences with the garden regarding the topic of this article.

### 3. A Park Between Low-Income Neighborhoods

Citizens initiated TG to make large and empty stretches of green grass livelier and more attractive. The Project for Public Places (2016) describes placemaking as a way of challenging and renovating socio-spatial infrastructures, most notably those inherited from modernist city planners. According to urban activists and sociologists, the functionalist organization of modernist architecture and planning leads to vast stretches of boring, empty, and unsafe green zones, car-dominated cities, and dull residential areas with scarce public space (Jacobs, 1961; Sennett, 2018). Jacobs (1961) was especially critical of the idea that cities could be designed on a drawing board. She analyzed the many desolate and violent places that resulted from such utopian city-making and, in contrast, described the richness of neighborhoods that developed organically, bottom up, with little interference from urban planners. Inspired by this critique, placemakers in the United States and other parts of the world promote walkability and tinker with small spatial changes and new connections to cultural, economic, educational, and other infrastructures to enable places to combine multiple functions.

The park that is in focus for placemaking by TG is situated between so-called “parochial neighborhoods” (Ziegler, 2010) that were designed as villages, with a church, shops, and a school located around a central square. Each neighborhood was separated from other neighborhoods by green zones (Figure 1). Over the course of time, church communities lost members, and small shops closed, as did many schools. Furthermore, sports facilities were concentrated in several big sports parks in the city, and the former soccer



**Figure 1.** Green infrastructure and “landscape-idiom” of parochial neighborhoods (Ziegler, 2010, p. 50).

fields between four parochial neighborhoods were converted into a park. This is the park in focus for TG. This green space was designed as a wedge between parochial neighborhoods with vistas as a reference to the surrounding countryside. However, the residents who initiated TG pointed out that, instead of a wedge, the space could become a bridge and a new social center connecting the surrounding neighborhoods. They stressed that the reference to the countryside was lost after new buildings blocked the view. According to TG, the spatial layout and infrastructure as meant by urban planners were outdated and in need of revision.

The neighborhoods surrounding the park have a history of being stigmatized as low-income that has left traces that remain today. Many families who first moved in were poor families who were forced to leave the city center in the 1950s and were framed as “antisocial” by scientists, church officials, social workers, and municipal officials (Bokern, 2022). Such stigmatizing neighborhood classifications continue in current research and data infrastructures that monitor urban health, demographics, income levels, the prevalence of anxiety, depression, being overweight, and other health issues, and they show on all fronts a worse-than-average picture. As urban governments, developers, housing corporations, and commercial enterprises often use these numbers in the planning and design of activities and to account for their activities to stakeholders and urban democracy, the stigma attached to these neighborhoods is continuously reproduced.

When, from the 90s onward, other city areas were restructured, the continued low rents of social housing organizations in Maastricht Northwest attracted new low-income residents, including residents coming from mental health institutions and different migration backgrounds. This development brought its own struggles and stigmatizations, as “old” and “new” residents rarely mingled. A TG member shared her experiences of going door to door on a certain street to invite people to a park event. She recounted what she heard about the neighboring households on that street:

There is a family that everyone talks about as antisocial. Next to that, on the corner, you have now a large Turkish family, and in the next house, the housing cooperation have now put a struggling family there. There you hear shouting, and they also have dogs, and there is a lot of noise and barking....and next to that there lives a Moroccan family, and next to that an Eritrean family, and then there comes a boy who is not very strong socially, and then comes a single father...so you don't have a community there...it's all a bit loose here...and the people who originally come from Maastricht with that dog that terrorizes the neighborhood....Because they have [such] different backgrounds...and the “we do it together” thing isn't so strong here.

The specific history of these neighborhoods affects social interactions between residents. People often annoy and avoid each other, and this poses an extra challenge when developing lively public places. As residents concluded at the citizens' summits: “We do not know each other anymore.” Next, we analyze the infrastructural work of TG to address that problem, the hostilities they encounter, and how they deal with them.

### ***3.1. Infrastructural Work and Emerging Publics***

Through their infrastructural work, TG members first assembled what could be described as pop-up publics. To make the park a vital part of the socio-material infrastructure of this city area, TG worked on social, spatial, ecological, and institutional connections. With a series of “light, quick, and cheap” actions (Project for Public Places, 2016, p. 635), TG experimented with small budgets and collaborations with various other

parties, such as students, architects, a folksinger, a dancing group, a welfare organization, and a nature organization, to organize activities in the park. New publics were invited to the park with sports, games, and theater workshops for children, a big Spring festival, a yearly Summer program, and several Summer campsite activities. During such campsite activities, the park was transformed into a neighborhood camping place for three days. Moreover, several Summer programs were held, including Dancing in the Park. Our Summer program field notes read:

On a small wooden dance floor with a DJ and a group of line dancers taking the initiative, other people slowly join in. The local born Maastricht people dance together with students from “the North,” Syrian children, and young parents from Ethiopia. A frail ninety-year-old widow sitting on a bench tells us that it is her birthday, upon which everyone starts singing for her. Later, she says that she had been crying at home as it was so long ago that she had experienced such a warm welcome.

These temporary transformations of the park produced new park and new neighborhood experiences. While the neighborhood was often labeled “backwards,” and the state of the park was taken as a symbol of political neighborhood neglect, these transformations provided new hope and perspectives. The park events assembled neighborhood publics with a great variety of geographic and religious backgrounds. Such a diverse constellation is rarely seen in other neighborhood meeting places, such as neighborhood centers, mosques, or churches, where people gather in smaller, less diversified groups or communities. People noted that, with some creativity, the park could become a vibrant place that would be safer with more people and more social control. The temporary transformations also had a longer lasting social impact, as one of the TG members noted: “I get greeted now by all the children in the neighborhood. That was different before.” The publics assembled by the park events can be termed “pop-up publics,” as they only formed on specific days to play, dance, and interact. However, despite their temporary character, the new social exchanges indicate that they left their traces in the park as part of a socio-material infrastructure enabling neighborhood interactions.

In addition to assembling pop-up publics, TG’s infrastructural work to revitalize an enclosed garden also led to the emergence of a more stable park public. Two residents noted that the garden had beautiful architecture but was neglected and overgrown with weeds. They joined TG and started working on the garden, weeding, and negotiating with the municipality (owner of the garden) about new plants, trees, furniture, and maintenance plans. Their work, the garden’s beauty, and their regular presence in the garden resulted in new people habitually visiting the garden and meeting others. A TG member recounted:

I don’t see everything, but many people say, “I come here very often,” or “I come here at least once every day.” And I now really notice that a schedule of regular visitors is really starting to develop, of people who come very regularly. People enjoy letting small children play, and more and more people are coming to walk laps. We sometimes have a man and a woman walking rounds, talking to each other for a full hour...and an Iranian woman who regularly comes to the garden to walk rounds with a friend...and what she also does is walk barefoot in the garden through the grass. Enjoying the grass,...and I have the idea that some frictions between residents in that flat building, that in the garden they are softened. For example, there are these two neighbors that never talk—they both come to the garden.

Through their presence working in the garden, TG members fostered new connections to people in the neighborhood, engaged new residents to help on the garden team, and developed new knowledge about

how people used and experienced the park. While the diverse park events assembled pop-up publics, the gardening enabled the formation of a more stable park public.

Park events and garden developments enabled a collective learning process about the physical organization of park space and potential improvements. The hot summers revealed that more trees, shadow areas, and comfortable benches were needed to attract people to the park. Children's games with small tree trunks generated new ideas to promote playability and attract small children with their parents. People shared their concerns and irritations with TG members about the lack of light, neglected park areas, dog excrement, and other nuisances, but they also expressed their appreciation for the flowers and the increasingly beautiful garden, with some wishes for wilder nature in the park. Based on these growing insights, TG developed proposals to promote the playability, pleasant seating, and nature experience of the park through more shadow with pergolas and trees instead of long open vistas, more comfortable benches, natural play elements, a kiosk, and a butterfly garden.

Over the years, some improvements in the spatial and ecological layout have been realized. With support from the municipality, a nature organization, and other parties, 46 new trees were planted, and a butterfly garden with wildflowers was sown. Moreover, hearing about the citizens' initiative, a nature education organization built a bees' hotspot in the park that is part of an exceptionally rich bee infrastructure in the city, hosting rare and endangered species, which is maintained with the help of citizens. However, many other potential improvements were not made. TG expects that a combination of three attractions in the park—namely, the garden; a nature playground financed by a local charity; and a kiosk with tea, coffee, and space for storing garden tools, financed by a municipal fund with the aim of promoting a habitable environment—will help to build a robust socio-material infrastructure. Working on this required intensive engagement with the municipality and other institutions related to the envisioned infrastructure. In these engagements, TG members experienced two types of challenges, in response to which they adjusted their infrastructural work.

### ***3.2. Infrastructural Work in an Obdurate and Ambiguous Environment***

The first challenge TG experienced was that the local government's promotion of citizen participation was accompanied by forms of institutional obduracy. This became manifest in municipal control over "the public" and the municipalities failure to give proper recognition to the emerging park public. With their participation in events and regular presence in the garden, neighborhood residents provided support for TG's efforts to improve the park's socio-material infrastructure. However, in interactions with TG, the municipality misrecognized this support and questioned the residents' right to speak. "In whose name are you here?" "Do you have support among residents?" "How can you show this?" With such questions about representation, the municipality positioned itself as the "controller" of public participation. Within the municipality, it is common to seek public input through questionnaires about specific predefined issues so that "the average resident" is represented. Even though many residents do not fill in these questionnaires, civil servants cling to the idea that it is possible to represent all residents. Moreover, historical informal classification systems shape ideas about support among residents. In response to a presentation about citizen participation in promoting healthy public space, a municipal official characterized TG as a small group of highly educated retired people, thereby contrasting them with other neighborhood residents and ignoring both the pop-up publics and the more stable park public assembled by TG actions. By taking a classical

political perspective of representation, assuming fixed preferences aggregated by a formal procedure at a fixed moment in time, the municipality discarded the knowledge built up through TG's years of intense engagement with the park's publics and the park as a public place. TG members were asked to give a quantified representation of a pre-given public and not to act as publicly engaged and highly knowledgeable residents who were constructing a socio-material infrastructure.

TG members shared their reflections on the resistance they encountered as a citizens' initiative in a meeting with several municipal officials. In this meeting, civil servants explained that citizen participation was complex for them:

We [municipality] are used to thinking that public space is ours when, suddenly, a group of residents wants to work on improving the park. That is fantastic, but it is completely new for us. We had never experienced that before. We must get used to that. And then we have these aesthetic norms. Benches should not be too cheap, and the green department is not about citizen participation. It was pioneering for us. (Field notes from the Spring 2022 meeting)

While TG proposed to share the responsibilities for maintaining the park space, the municipality took a strong dichotomous approach: it is either the municipality's or the citizens' responsibility, and when citizens take over, they must position themselves as representatives of the neighborhood. TG responded by claiming their right to speak, not as representatives but based on being residents ("I live here!") and being especially knowledgeable because of their regular presence and work in the park.

A second challenge experienced by TG was the municipality's ambiguous bureaucratic way of responding to TG's participation. In the context of broader citizen participation movements, the municipality combined positive support for plans with letting recommendations go ignored, failing to follow up, failing to respond, and refusing to interact. For example, TG's insights about places for shadow, protection, and benches were disregarded, and emails with questions about the proposals of municipal designers went unanswered for months. Moreover, the nature playground could only be realized when the funding charity and the municipality agreed on tender, quotation, and billing. However, both institutions seemed unwilling to interact, leading TG members to walk back and forth in circles. During a TG meeting, one of the members remarked: "About the 'stiff-fund' [a nickname for the local charity], this is driving me crazy. Perhaps we should call it off." The location of the nature playground was chosen by municipal designers based on aesthetic judgment. This choice completely disregarded TG's recommendations based on multiple observations in the park. The municipality located a circle of play sand on two sides of the path used by dog walkers:

More wrong is almost impossible. It is a path where people with dogs walk, and you do not have to be very mal-educated to be attracted to that sand [as a dog or dog walker]. (TG member interview)

The nature playground did not work out as imagined. It did not attract children or parents, and after the festive opening with the director of the funding charity and an alderman, the playground became a painfully visible failure in the park. While civil servants point to TG as the initiator of the plan, TG feels that it could have worked out better had TG's perspective been taken more seriously.

### 3.3. Building New Alliances and Engaging in Garden Diplomacy

In this obdurate and ambiguous institutional bureaucratic context, TG responded with two types of infrastructural work: building new alliances and engaging in garden diplomacy. Building new alliances to promote the park's socio-material infrastructure meant that TG first had to slow down. TG continued to maintain relations with the municipality by staying in touch about envisioned meeting places and the renewal and maintenance of the garden. They had no choice but to endure the setbacks and slow their pace while looking for new ways forward. While TG had found funding for a kiosk, conversations about the actual installment had been going on for years, and the two sides ended up in a deadlock with no clear directive on how responsibilities of the municipality (owner of the park) and those of TG should be handled:

At first, we expected too much from the municipality as it is the owner and wants to be engaged in every step. But the municipal contacts looked at us like, let's see what you want. And we felt blocked by the municipality, which told us to first get a permit, first get water, first get electricity. And if you are sure that everything will happen, then the kiosk can be installed....And we said, we don't want to run the risk of having everything ready and then you, as the municipality, say, sorry, there is no permit. (TG member interview)

One way to build new alliances was through the park seminar, which brought together residents and some professionals working for a welfare organization and a nature organization to reflect on the park and prioritize actions:

I thought it was fantastic that we had a room full of people who all contributed so actively. And after that, I think it's disappointing...not because of us, but it still comes down to us. We got stuck in that...because we were going to work on that kiosk after the park symposium. (TG member interview)

When follow-up on the park symposium was cancelled, some TG members had another meeting with the municipality. This time, TG was advised to apply for the permit to install the kiosk anyway, as "the municipality will not act unless there is a formal application." So, TG submitted the permit application, not expecting success soon, but considering the permit application as the start of another long-term negotiation process.

TG's second response to the ambiguity of both supportive and unreliable bureaucratic engagement was a form of "garden diplomacy." Diplomacy in international relations is commonly seen as the art and practice of maintaining peaceful relations, and diplomats are positioned as negotiators and as the eyes and ears of a government. With garden diplomacy, we refer to the practice of maintaining and building constructive relations between neighborhood residents and the municipality in all interactions in the garden. In the garden setting with the regular presence of and contact with both residents and the municipality, TG members worked on bridging and ameliorating old contentions between neighborhoods and the municipality. Like diplomats, TG members also saw the different faces of the municipality, formally and sometimes practically embracing participation while at the same time creating obstacles to participation. The garden team functioned as the eyes and ears of the garden, and as diplomats, they heard and saw the ambivalence in the park's public, for example, about the installation of arches forming a so-called *berceau* (tunnel) along which a *Laburnum* (golden rain tree) will be trained:



When that berceau came there, I was also curious about what the neighborhood would think. And I also hear “what have they come up with” and “how much does that cost,”...but there are also people who say: “I think it’s really chic; it is special.” People give me thumbs up. (TG/garden team member interview)

With their garden diplomacy, TG members faced confusion about their position and had to remind residents that they were there as citizens caring for the park and garden, not as part of the municipality:

Sometimes we are seen as part of the municipality, unless people know us. Then they say [in dialect]: “Yes, but we always see you...no this [critique] is not about you.” (TG/garden team member interview)

Sometimes, when picking up garbage, other residents tell TG members: “The municipality should do this.” TG members explain that they value the engagement of citizens in the making of the neighborhood and that they have an agreement that the municipality will do major maintenance and that TG will take care of litter in the park every three to six weeks. This garden diplomacy involved a complex balancing act because when the municipality made mistakes, TG refrained from complaining while at the same time staying wary of being held accountable for municipal mistakes.

The difficulty in promoting a livelier park was viewed by the municipality and other institutions as yet additional confirmation of the problematic nature of these neighborhoods: They tried but failed because of the lack of participation of the whole neighborhood. On the other hand, participation by residents with higher levels of education meets with skepticism because they do not fit the institutionalized ideas about these neighborhoods as poor and poorly educated. Our analysis of infrastructural work by TG members and the obduracy and ambiguity they faced also shows that “the problem neighborhood” with low participation and cohesion is reproduced in interactions with the municipality. The interactions are characterized by strong institutional control and unreliable support that seriously challenge the engagement of citizens in promoting a healthy environment.

#### 4. Conclusion

Citizen participation forms an integral part of the healthy city movement and has almost acquired the status of the gold standard for city planning and development. However, the reliance on specific formats, time windows, and accountability structures makes citizen participation susceptible to dynamics of inclusion and exclusion, prescribing who can participate, when, and how. Citizen initiatives operate in a complex context, characterized by support as well as obduracy and ambiguity. The case of TG shows how the notion of infrastructural work elicits citizen engagement in building common urban worlds, placed in this complex context.

TG engaged in constructing a socio-material infrastructure by redesigning and maintaining a large, empty park. As their infrastructural work enabled the emergence of new publics—promoting friendliness, public familiarity, and helping hands between residents from diverse backgrounds—TG challenged the persistent classification of the neighborhood as antisocial, non-participatory, and problematic. However, TG’s efforts to improve neighborhood life faced two challenges. On the one hand, encouragement of citizen participation was accompanied by institutional obduracy through expertocratic control over public space and “the neighborhood public,” and on the other hand, bureaucratic interactions proved ambiguous as they were unpredictable and unreliable. In this context, TG’s infrastructural work was characterized by the



maintenance of institutional relations, by slowing down and adapting to the rhythms of institutions like the municipality, and by engaging in garden diplomacy to maintain hopeful and constructive relationships with residents as well as institutional partners. For TG, maintaining both the precarious socio-material infrastructures they developed and their relationship with the municipality required quite some endurance.

Even if members of TG convince each other and neighborhood residents that this obduracy and ambiguity should not be regarded as hostilities, the analysis helps to gain insight into an institutional environment that is hostile to uninvited bottom-up forms of citizen participation. This hostility can be considered in light of a blindness in participatory policies and research for the unstable, co-productive character of publics. Following Chilvers and Kearnes (2016), we suggest this blindness stems from a “residual realist account” of a public that exists objectively, outside, and independently of research and policies. While social constructivist perspectives of objects—such as trees or benches that can become resources or nuisances—are familiar in research and policies, a residue of realism remains with respect to understanding and approaching subjects, the publics participating in the development of green space. This was also the case in Maastricht Northwest, where the municipality considered the neighborhood public and their opinions as given, to be discovered with questionnaires using pre-given social status classifications. The emergent publics that did not match this neighborhood picture were dismissed as not representative of neighborhood residents. This “old” realist approach to neighborhood publics, thus, reproduced the stigmatized “antisocial” neighborhoods and cut off the attempts to develop new neighborhood publics in the process. Such realist approaches to “problem neighborhoods” are not exceptional to our case; similar processes of reproducing problem groups and problem neighborhoods in institutional interactions have been described in other urban settings (e.g., Diers, 2004; Montoya, 2013). Montoya (2013), for example, pointed out how potential futures of Central City in Los Angeles are thwarted by narratives and statistics of deficits that require repair or removal before any other actions find support.

Our analysis contributes to discussions about relationships between infrastructuring and participating publics. Whereas in the literature on the co-production of issues, infrastructures, and publics, contestation and controversy play a central role (Baringhorst et al., 2019; Chilvers & Kearnes, 2016; Korn et al., 2019; Latour, 2005), our analysis foregrounds mundane socio-material practices more than contestation. In an edited email discussion about relations between infrastructures and publics, Marres (in Baringhorst et al., 2019) observed that new publics are formed around issues and by taking issue with existing or developing infrastructures. Pedestrian activists like Peatónito present a typical example of this issue-making as they publicly demonstrate the problems of traffic that make cities inhospitable for people without cars. TG members also take part in a public that emerged around the issues of loss of social meeting places and scarcity of city nature. However, residents who became part of the wider publics that formed together with the initial TG initiatives did not form a typical issue public, but rather a public that participates by engaging in material practices. Marres and Lezaun (2011) argued that material practices in themselves, even the mundane, everyday material entanglements, can be approached as forms of citizen participation and that material objects and settings are part of the organization of publics. Our analysis shows how residents participated in the park’s socio-material infrastructuring with their material practices of regular walks and garden visits, help with gardening, litter pickup, picnics, and festivities. Compared to Peatónito, gardening, daily garden walks, and social interactions in the park may be less visible to the municipality, sunken into the infrastructure of the park. However, in a neighborhood pluriverse, these material practices become constitutive of a shared world. Even residents who do not join the garden group appreciate and

trust that every Tuesday and Saturday TG members are working in the garden, as a social rhythm of the neighborhood.

This perspective on material public participation in turn contributes to discussions on the remaking of participation from a co-productionist perspective (Chilvers & Kearnes, 2016). Literature on co-production between participatory technologies and publics points out how participatory formats perform specific publics (Voß, 2016). Voß and Amelung (2016) reconstructed participation method developments over four decades and observed how anti-technocratic citizen participation transformed into technological expertocratic control over participation methods and their political legitimacy. This expertocratic control, however, met with reflexive critique, re-placing citizens' matters of concern at the center of public participation. In our analysis, TG replaced institutionalized participatory technologies, such as surveys, signatures, or roundtable discussions, with material practices of gardening and experimenting in the park. The infrastructural work of experimenting and gardening can be regarded as participatory technologies performing a public that participated in building a common "neighborhood cosmos." When their validity was challenged or ignored, TG modified their participatory technologies. Adjusting to a hostile environment, gardening became garden diplomacy, in which the garden mediated constructive socio-material relationships between neighborhood and municipality.

Finally, our long-term collaborations with TG and related participatory collectives in UwtN also provided insights into pathways for remaking citizen participation. Our pathway to remaking participation was formed in response to worries about top-down technocratic control over participation and concerns about the aggravation of inequalities that result from the participatory turn (Calhoun, 2015; Polletta, 2015; Voß & Amelung, 2016). While many researchers and policymakers worry about hard-to-reach low-income groups (Knibbe et al., 2016), we approached this as a relational problem. Health inequalities should and will not be solved by seeking to include specific "problem groups," as this approach easily reifies and stigmatizes low socioeconomic status (which is a relational qualification) into "LSES groups" (Dijkstra & Horstman, 2021). Instead, health promotion and research for healthy cities should work on making relations of collective action and research more accessible by being present on a regular basis in a variety of roles and places in low-income neighborhoods. Such accessibility and presence enable the recognition and support of forms of citizen participation and building neighborhood commons that remain unnoticed or are easily thwarted in a participatory ideology that celebrates new initiatives, deliberative formats, and methodological approaches to public participation.

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## Conflict of Interests

The author declares no conflict of interests.

## Data Availability

Our data are rich with detail and not sufficiently anonymized for public availability. They are, therefore, stored in a secure repository at Maastricht University. Upon reasonable request, parts of our data that are easily anonymized can be made available.

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## About the Authors



**Mare Knibbe** is an assistant professor in the philosophy of health sciences at Maastricht University in the Netherlands. Her research explores new ways to promote the health and resilience of disadvantaged city areas, neighborhoods, and groups and examines the making of public space and the diverse “publics” of health promotion and city life. She uses participatory and ethnographic methods and crosses disciplinary boundaries between sociology, philosophy, and science and technology studies. She was trained in religious studies, bioethics, and care ethics and conducted her doctoral research about ethical perspectives on living donor liver transplantation.



**Sanne Raap** studies the intersection of citizen participation and health in low-income neighborhoods. She focuses on the different ways citizens participate in their neighborhoods and theorizes the relation between citizen practices and public health. She studied Philosophy and International Relations and her research interests include urban sociology and science and technology studies. At the moment she is finishing her dissertation on healthy neighborhoods.



**Klasien Horstman** studied philosophy, historical sociology, and science and technology. She is a professor of philosophy of public health at Maastricht University in the Netherlands. Her research is dedicated to exploring the “public” character of public health and the engagement of public health experts and policymakers with different “publics.” She uses philosophical-empirical, participatory-ethnographic methods to study relationships between science, society, and democracy in a variety of public health practices, such as (workplace) health promotion, urban health, vaccination, and antimicrobial resistance prevention.



# Public Participation in the Time of Covid-19: Response From the International Disability Movement

Hanxu Liu <sup>1</sup> and Claudia Coveney <sup>2</sup>

<sup>1</sup> Care and Public Health Research Institute, Maastricht University, The Netherlands

<sup>2</sup> School of Sociology and Social Policy, University of Leeds, UK

**Correspondence:** Hanxu Liu ([hanxu.liu@maastrichtuniversity.nl](mailto:hanxu.liu@maastrichtuniversity.nl))

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## Abstract

This article examines attempts by the international disability movement to influence Covid-19-related policy by becoming involved in high-level decision-making processes and advocacy activities. Global emergencies like the Covid-19 pandemic limit opportunities for citizen engagement in governance. Like other marginalised groups, persons with disabilities faced increased exclusion in this period, including barriers and lack of opportunities to participate in public decision-making processes via civil society. The de-prioritisation of their lives and opinions was evident in many countries' initial approaches to containment and treatment, contributing to an excess risk of death among persons with disabilities. International legal instruments like the UN Convention on the Rights of Persons with Disabilities, ratified by 191 (state) parties, affirm persons with disabilities' right to participate in all public affairs as crucial for their equality and inclusion. This article defines the scope of public participation of persons with disabilities under international human rights law and employs a document analysis of public and grey literature from civil society organisations and international institutions of governance. This analysis examines the barriers preventing persons with disabilities from participating in Covid-19-related policy and decision-making and explores how a representative organisation—the International Disability Alliance—utilised existing channels and created new spaces to amplify their voices globally. To do this, we utilise the concept of “invited and invented space” and demonstrate the strategic response of the movement to barriers to public participation during the global pandemic.

## Keywords

Covid-19; disability rights; emergency policymaking; international disability movement; public participation

## 1. Introduction

In this article, we focus on the public participation of persons with disabilities and their representative organisations in decision-making and policy settings concerning the Covid-19 pandemic. Within international human rights instruments, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), the term “barriers” is used to describe economic, social, political, and environmental phenomena that hinder the “full and effective participation and inclusion in society” of persons with disabilities in everyday lives. Barriers to participation can be observed in contexts ranging from research activities, reproductive choice, education, employment, political participation, and community life, to intimate relationships and end-of-life decisions (see, e.g., Kim et al., 2016; Plosky et al., 2022; Priestley et al., 2016). In keeping with disability studies and legal frameworks, our focus is on the barriers experienced by persons with disabilities during the pandemic, specifically those relating to participation in public decision-making. In this context, we also examine the response of an international organisation of persons with disabilities (OPD)—the International Disability Alliance (IDA), especially its efforts to influence the international decision-making processes related to Covid-19. The international monitoring body of UNCRPD—the Committee on the Rights of Persons with Disabilities (CRPD Committee)—has defined OPDs as those “led, directed and governed by persons with disabilities,” who have been the main participants in disability rights movement (CRPD Committee, 2018, para. 11; Sabatello, 2013). Here we examine the dynamics of international commitments and the obligations stipulated in international human rights law and governance to include and consult OPDs on policy matters concerning disabled people in the pandemic.

Reflecting on Zvonareva and Egher’s (2025) discussion in the introduction to this thematic issue on indirect hostilities to participation, being those that “operate to limit or circumscribe participation to particular pre-framed questions, controlled formats, or selected groups,” and “justifying selective invitations for some and uninvitations of others who are framed as having less right to participate,” we find parallels with discussions in disability studies around exclusion and tokenistic inclusion (see also, e.g., Farooqi & Ali, 2023; Friedman et al., 2016). We return to the relationship between “indirect hostilities” and disability-related barriers at the end of this article.

Disabled populations were constructed as a particularly vulnerable group during the pandemic globally (Perry et al., 2020). In some cases, this was due to pre-existing health conditions that would exacerbate the impact of the virus on some groups. In other cases, vulnerability stemmed from the living conditions of groups of persons with disabilities—for example, those living in large-scale institutions, or from unequal outcomes due to health inequity experienced by persons with disabilities. Examining the experience of disabled people in Covid-19 responses, Shakespeare et al. (2021) find their exclusion from crucial services such as food deliveries, Covid-19 testing, and the internet. The authors highlight a de-prioritisation of disabled people and their families or support workers in vaccination and treatment schemes and a particular failure to ensure the safety of disabled people in institutionalised living settings. This is the context in which civil society organisations representing the interests of disabled people were conducting advocacy work during the pandemic. The participation of organisations representative of persons with disabilities was therefore particularly pertinent in decision-making processes during the pandemic.



## 2. International Legal and Governance Context

The international political movement of disabled people has a documented history of collective action and strategic mobilisation, as reflected in their decisive role in the creation of the UNCRPD (Driedger, 1989; Sabatello, 2013; Trömel, 2009). As we will elaborate later in this article, much of this international movement is present within the ranks of the IDA. IDA works closely with supranational organisations such as the UN in disability rights and affairs, aligning its activities with those of the UNCRPD (IDA, 2024). IDA was established in 1999 as a network of global and, since 2007, regional organisations of persons with disabilities and their families. Together with its member organisations, IDA attempts to influence legislation, fund programmes, and advocate for disabled people around the world. The present section outlines the legal and policy context of the participation of OPDs during Covid-19.

According to international policies and human rights norms set before the Covid-19 pandemic, countries have the legal and political obligation to involve persons with disabilities, through OPDs, in decision-making, implementation, and monitoring processes related to the Covid-19 pandemic, including its prevention, mitigation, preparedness, response, and recovery plans. The UNCRPD is the main international normative framework on disability human rights protection. This legally binding instrument represents a paradigm shift to the human rights model in disability policy, recognising persons with disabilities as subjects of rights rather than as objects of charity, medical treatment, and welfare policies, as is the traditional approach to disability (Degener, 2017; Lawson & Beckett, 2020). As of 2023, only a few UN member states, including the USA, have not ratified the UNCRPD. Articles 4(3) and 33(3) of the UNCRPD envisage a general obligation for states to “closely consult with and actively involve persons with disabilities” in the development, implementation, and monitoring of laws and policies relating to the UNCRPD, and in other general decision-making processes “concerning issues relating to persons with disabilities.”

The obligation to consult people with disabilities applies to biological disasters such as epidemics and pandemics, as well as other situations of risk and humanitarian emergencies under Article 11 of the UNCRPD (Lewis, 2020). Specifically, this obligation should be conducted through the representative OPDs, including representative organisations of children with disabilities (CRPD Committee, 2018). States and humanitarian actors are required to ensure “the active participation of and coordination and meaningful consultation” with a diverse group of OPDs in the planning, implementing, and monitoring of emergency-related laws and policies (CRPD Committee, 2018, para. 78). Several international policies have incorporated this principle. The Sendai Framework for Disaster Risk Reduction 2015–2030 emphasises that all disaster risk reduction policies and practices should be inclusive and accessible to people with disabilities as a general principle. This intergovernmental document, adopted by a majority of UN member states (187), aims to guide national, regional, and international actions for disaster risk reduction in 15 years (UN Office for Disaster Risk Reduction [UNDRR], 2015). It applies to the risk of a range of disasters caused by natural or man-made hazards, including biological hazards such as epidemics and pandemics. Disaster risk governance involves several key phases, including “prevention, mitigation, preparedness, response, recovery and rehabilitation” (para. 26). States are obliged to engage with OPDs in the design and implementation of policies, plans, and standards at all levels of the government, as well as provide disaggregated data based on disability, among others, to form the basis of “inclusive risk-informed decision-making” (UNDRR, 2015, para 19; see also Lewis, 2020). Inclusion and participation of persons with disabilities is also one of the main working areas of the 2030 Agenda for Sustainable Development Goals (SDGs) under the principle of “leaving

no one behind” and underpinned by human rights (UN General Assembly, 2015). The SDGs provide “a comprehensive blueprint for [a] sustainable recovery from the pandemic” (UN, 2020b).

In the international policy guidance and advice issued in relation to the Covid-19 response and persons with disabilities, the UN and its agencies have reiterated the importance of the participation of OPDs in the relevant policymaking process (see, e.g., UN, 2020a; UN Department of Economic and Social Affairs [UNDESA], 2023; for a detailed review see also Lewis, 2020). As a principle, engagement with and participation of persons with disabilities and OPDs in Covid-19-related decision-making should be followed by all UN entities.

### 3. Existing Research: Civil Society, Engagement, and Covid-19

We situate our investigation into the international disability movement alongside perspectives on civil society engagement in periods of crisis in governance. The following section contextualises our investigation in terms of relevant research relating to civil society participation during the pandemic, particularly its underutilisation, and strategies used by organisations to overcome these barriers—including the channels they used to do so. We discuss what is known about civil and community engagement in the context of Covid-19: namely that engagement, despite being critical during emergencies and crucial for ensuring context-relevant responses, was not used in most cases by governments in their responses to the pandemic (Sahoo et al., 2023). We use this literature to demonstrate that what Zvonareva and Egger (2025) identify in the introduction to this thematic issue can be found in the context of international civil society engagement in governance processes: Despite discursive support for public participation (via representative civil society organisations), in practice this participation is often limited by institutions of governance rather than enacted meaningfully.

In the early international response to the Covid-19 pandemic, contexts where civil society was activated and empowered to contribute to responses to the pandemic showed better outcomes in terms of service delivery, health and prevention messaging, and localised responses in communities relative to contexts where civil society was blocked from participating or ignored in government responses to the pandemic (Kövé, 2021; Sayarifard et al., 2022). Writing for the World Health Organisation (WHO), Rajan and Koch (2020, p. 27) found that, across national contexts, “civil society and community groups were poorly or not at all represented on Covid-19 advisory task forces” and these task forces “largely involved governments telling communities what to do, seemingly with minimal community input.” Garcia et al. (2023) discuss the consequences of reduced revenue and access to funding for civil society during the pandemic and note that where collaboration between civil society and local governments did occur it opened up new roles for civil society. Civil society and community groups offer services including risk communication and peer support and contribute particular knowledge and legitimacy resources to government decisions but were not largely utilised by policymakers. Rajan et al. (2021) pointed to the success of systems where participation mechanisms for civil society improved the efficacy of government responses to the pandemic. Discussing the “anchoring” of participatory mechanisms, Rajan et al. (2021) note the importance of legal frameworks and adequate, ongoing funding for such interactions. However, the “default” mode of governance in most contexts ignored the contribution of civil society “where trust in institutions and adherence to virus mitigation measures can make or break the success of the pandemic response” (Rajan et al., 2021, p. 28; see also Falanga et al., 2021; Marston et al., 2020). Focusing on the participation of people with disabilities and their representative organisations, McVeigh et al. (2021) note that, on top of the barriers other groups face,

OPDs face specific barriers to participation, including “poverty, lack of education, social isolation, stigma and discrimination, lack of disability-accessible processes, and legal barriers” (p. 214). The authors conclude that people with disabilities and OPDs experience systemic exclusion from decision-making and consultation on policies, practices, and services that affect their lives. This contributes to unequal access to political processes and results in political disablement.

Examining the impact of the pandemic on civil society participation relating to migrants, Rother (2022) notes that hostilities towards a rights-based approach to migration intensified. This is despite these local groups being embedded in communities and well-placed to access those disproportionately affected by the pandemic including older people, disabled people, single parents, and migrants. Rother (2022) examines the structures of political opportunity for civil society that have been created by institutions of governance (where civil society is “invited”) on the one hand and, on the other, those created by civil society itself (which civil society has “invented”). Paying attention to specific transformations in communication during the pandemic—like the “zoomification” of meetings—Rother notes that some of these developments increased openness and inclusivity for civil society. Both “invited” and “invented” spaces for civil society grew in scope and depth during the pandemic and have likely created permanent new spaces for migrant civil society despite noted barriers. Such a study has yet to be conducted on the disability advocacy movement. Using Rother’s (2022) framework, in this contribution to the literature, we examine how invited spaces have been used by a key international disability advocacy organisation to address the exclusion faced by disabled people and OPDs during the pandemic. We focus on the activity of the international disability movement and international governance structures to examine how the movement used existing modes of participation to create new spaces to advocate for the rights and wellbeing of disabled people in the Covid-19 context. We add the perspective of the disabled people’s movement to this examination of specific group experiences of barriers in the pandemic and explore how the UNCRPD as a framework was upheld or contested. We also investigate the emergence of invented spaces and the strategies used by a key disability advocacy organisation to utilise and create channels of participation and influence Covid-19 policy decisions.

We have established that disabled populations globally were disproportionately impacted during the pandemic (particularly those living in institutions) and that disabled people and OPDs face additional barriers to participation in comparison to other civil society organisations. We argue that these two factors warrant an examination of the particular experiences of OPDs in the context of public decision-making during the Covid-19 pandemic, particularly the strategies they have employed to participate amid barriers. We can understand civil society as the primary conduit for formal participation by social movements like the international disability movement in governance (see Della Porta, 2020). We will look at the response of the movement via its international civil society representative (IDA) in the context of international policymaking processes during Covid-19. This leads to the particular research question we attend to in this article:

How did the international disability movement respond to barriers to participation encountered by persons with disabilities during the Covid-19 pandemic in international policymaking processes?

## 4. Methodology

Following the main research question, we conducted a document analysis of grey literature and UN documents to examine the participation of IDA in Covid-19 policy decisions in international organisations. Grey literature

refers to materials and research produced by relevant organisations outside of traditional academic publishing and distribution channels.

An analysis of documents and grey literature is appropriate here to analyse activities by the disability movement that were not covered in extant academic research (Bowen, 2009). We selected relevant grey literature and other documents from the start of the pandemic, the very end of 2019, until the end of 2022 to capture the fullness of policy responses and the international disability movement's activity over the initial and later stages of the pandemic. Key policymaking events in the Covid-19 timeline will be reviewed in the next section.

We selected a representative international OPD as our focus. IDA is an international “umbrella” disability advocacy organisation. “Umbrella” here refers to the structure of the organisation: Its members are global and regional organisations of disabled people and their families. In turn, these organisations consist of regional, national, and local OPDs. At the time of writing, IDA membership consisted of six regional (Africa, Americas, Asia, Europe, Middle East and North Africa, and Pacific) and eight global ODPs representing persons with disabilities and their families in over 200 countries and territories. Global ODPs include the World Blind Union and the World Network of Users and Survivors of Psychiatry; regional members include the African Disability Forum and the European Disability Forum. IDA is governed by its full members and through the IDA Board, which is made up of representatives from each of its full members. All IDA members are organisations majority-led by and composed of persons with disabilities and their families. IDA is recognised to be an organisation representative of the wider disability movement, acknowledging no one organisation can represent every faction of a social movement. Nevertheless, this organisation is a major and key representative organisation of the international disability rights movement, particularly noted for its instrumental role alongside its member organisations in the creation of the UNCRPD (IDA, 2024; Sabatello & Schulze, 2013; Trömel, 2009). Nowadays, IDA activities span from high-level advocacy work with the UN system and other UN agencies like the WHO to ensure actions align with the principles of the UNCRPD and to work with states and other NGOs to mainstream the rights and interests of persons with disabilities in other human rights and development initiatives (IDA, 2024; WHO, 2024;).

The activities of IDA, including its member organisations, are comprehensively documented on its website (<https://www.internationaldisabilityalliance.org>). The Office of the High Commissioner of Human Rights (OHCHR) website, the World Bank Open Knowledge, and repository searches were also used for searching. The search function of each website was used by combining the keywords “COVID(-19),” “persons with disabilities,” and/or “disability(-ies).” The search results were reviewed and further narrowed down according to the configured filters, including the time period (2019–2022) and the group of rights and persons. After that, only results related to the participation and involvement of OPDs were selected: 89 documents were divided into five categories and analysed, as shown in Table 1. Finally, the documents were coded and analysed under three themes (*barriers*, *participation in Covid-19 policymaking*, and *actions*), which were identified according to the research question. The coding processes also identified a couple of new themes related to the strategies used by IDA and other OPDs.

**Table 1.** UN documents and grey literature selected for document analysis.

Document type	Number
Concluding observations issued by three UN treaty bodies	29
UN news, statements, and resources	14
World Bank document/research	1
Output from or contributed by IDA and its member organisations	45

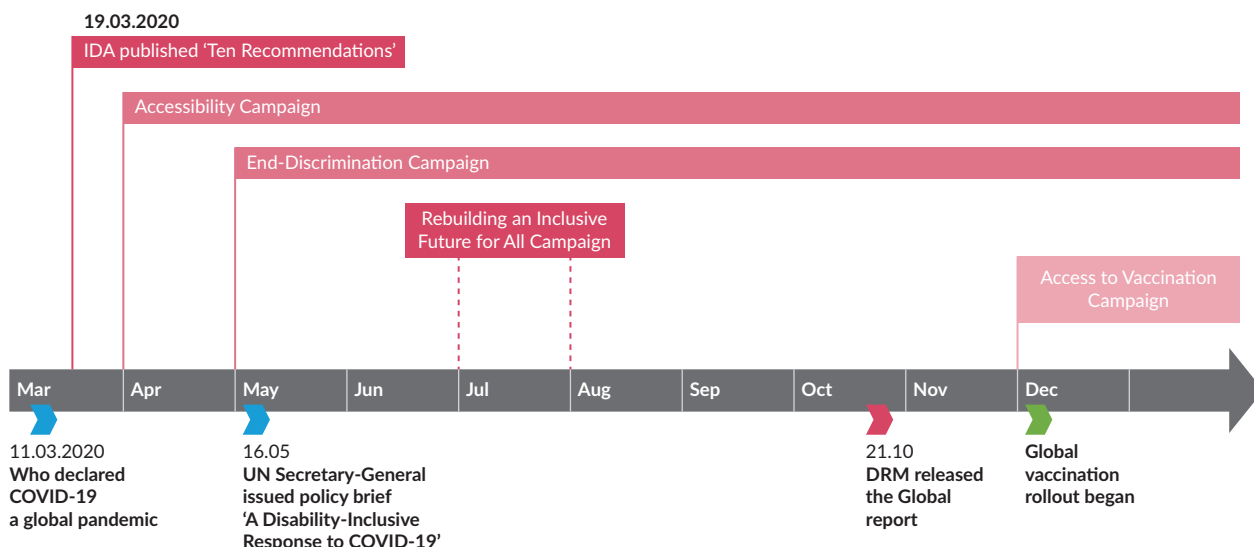
## 5. Findings

The findings draw attention to two themes: (a) the barriers encountered by persons with disabilities during Covid-19, which hindered their participation in decision-making processes, and (b) the strategies employed by IDA in order to influence international decision-making processes to address these barriers. Additionally, the findings discuss the organisation’s role in relevant international decision-making bodies and the corresponding responses it received. In conversation with existing literature, in particular the concepts of “invited” and “invented” spaces for civil society participation in global governance (Rother, 2022), we will delineate how IDA utilised both spaces to participate in international policymaking processes despite the barriers to public participation experienced by disability communities.

### 5.1. An Overview of Key Actions From IDA

IDA has actively responded to the challenges posed by the global pandemic. Most of its major actions and campaigns were launched in 2020, coinciding with the global policy responses to the pandemic, and continued until 2021 (see Figure 1). The organisation released the document *Ten Recommendations on Disability-Inclusive Covid-19 Response* (hereinafter, *Ten Recommendations*) a few days after the WHO announced the Covid-19 outbreak as a global pandemic (IDA, 2020a). The *Ten Recommendations* were compiled based on inputs received from IDA members around the world at all levels, in response to the pandemic and its “disproportionate impact on persons with disabilities” (IDA, 2020a). This document serves to reveal the common main barriers faced by persons with disabilities and to offer practical recommendations to ensure their inclusion in the Covid-19 response and its practice. It focuses on four themes: access to preventive measures, vital service provisions in restrictive programmes, seeking health care, and the participation of local and national OPDs in decision-making and implementation processes. IDA emphasises the key role of local and national OPDs in the Covid-19 response, such as raising awareness about the pandemic among members and advocating for disability inclusion in national and local crisis response policies and implementation.

The *Ten Recommendations* represent the two working areas of IDA during the pandemic, namely accessibility and disability non-discrimination. Together with its members and allies, IDA later carried out four campaigns with specific themes (see Table 2), namely the Accessibility Campaign, the End-Discrimination Campaign, the Rebuilding an Inclusive Future for All Campaign, and the Persons with Disabilities and Access to Covid-19 Vaccination Campaign (hereinafter, *Access to Vaccination Campaign*). These campaigns were based on the working areas and themes highlighted in the *Ten Recommendations*. IDA has engaged in five types of transnational advocacy activities, including research and publications, reporting, capacity building, media campaigns, and coordinating the global disability movement. In terms of



**Figure 1.** Timeline of Covid-19 and main campaigns from IDA in 2020.

**Table 2.** An overview of IDA's public campaigns.

	Activities	Demands	Audiences
<b>Accessibility Campaign</b>	open letters, social media campaign toolkits	access to all public information and communication at the UN system and among its Member States	High-level officers at the UN system
<b>End-Discrimination Campaign</b>	open letters, social media campaign toolkits, oral statements, written submission	end discrimination against disability that existed in Covid-19 response and recovery policies, including public health, economic and social policy, and healthcare measures	UN member states, health service providers, and other relevant actors
<b>Rebuilding an Inclusive Future for All Campaign</b>	oral statements, NGO side events	disability inclusion in general SDG-related emergency response policy, including implementation and monitoring of Covid-19 response and recovery practice	UN system, member states, and other attendees of the 2020 High-Level Political Forum on Sustainable Development
<b>Access to Vaccination Campaign</b>	Social media campaign toolkits, toolkits for national advocacy, capacity-building, coordinating global disability movement	priority, accessibility, and inclusion of persons with disabilities in relevant Covid-19 vaccination rollout policy planning, revision, and practice	The UN system, National stakeholders and general public, including: national health system, media, the national crisis response headquarters, national education authorities, and relevant private sectors

research and publications, the organisation conducted and participated in several international surveys on the lived experience of persons with disabilities during the global pandemic (IDA, 2021a). These include a global report issued by the Covid-19 Disability Rights Monitor (DRM) initiative, in which IDA coordinated with six other disability rights organisations (Covid-19 DRM, 2020; Mladenov & Brennan, 2021). In an initiative titled *Voices of People with Disabilities During the Covid-19 Outbreak*, IDA and its member organisations conducted an open call for story submissions from persons with disabilities around the world on how their lives were affected by the pandemic and related policies and measures on the ground.

## 5.2. *Barriers to Participation and Response From IDA*

A significant amount of IDA's advocacy efforts have identified the barriers encountered by persons with disabilities in public participation during the pandemic or due to related policies and their implementation. Some of these barriers resulted in the exclusion of OPDs from public decision-making processes. According to the grey literature IDA authored or contributed to, OPDs and persons with disabilities were not properly consulted or involved in the Covid-19-related policy and practice on the ground. These findings are consistent with the observations made by the CRPD Committee. Under the periodic state reporting procedure between 2021 and 2023, The CRPD Committee has criticised the lack of involvement of OPDs in Covid-19 response and recovery plans in its concluding observations concerning 22 countries (in total 29 States under review) from Asia, Europe, Oceania, and South America. For instance, in its concluding observations on Germany's periodic report, the CRPD Committee (2023, para. 23) has concluded that:

The lack of close consultation with and active involvement of persons with disabilities through their representative organisations in...the planning of Covid-19 pandemic mitigation responses that resulted in adverse impacts on persons with disabilities.

Furthermore, the Committee has addressed some common barriers persons with disabilities have encountered, including the disproportionate impact of the pandemic on persons with disabilities (15 countries); lack of access to Covid-19-related information and healthcare services (9 countries); and lack of data on the impact of the pandemic on the disability population (3 countries). Similarly, IDA's campaigns and other advocacy efforts have highlighted four types of barriers that have directly or indirectly hindered persons with disabilities or OPDs from participating in the development, implementation, and monitoring of national Covid-19-related policies and measures. The organisation then participated in various international channels and platforms in response to these barriers. The following subsections examine how these barriers—specifically the lack of accessibility provisions, disability-related discrimination and exclusion, lack of capacity, and lack of data—have affected the public participation of persons with disabilities and OPDs.

### 5.2.1. *Lack of Accessibility Provisions*

IDA identified the lack of access to information, communication, and physical environments as one of the main barriers that persons with disabilities experienced during the global pandemic that inhibited their public participation. Inaccessible information and communication regarding the pandemic response have been reported across all levels. This includes a lack of accessible and alternative formats of information and communication tools for Covid-19-response-related public services, such as providing sign language interpretation, easy-to-read, and audio descriptions in government briefings and press conferences.



For instance, IDA's study indicated that the preventive and restrictive measures implemented imposed communication barriers, which will have implications for their participation in public consultations. IDA (2021a, p. 43) cites a man with deafblindness from Norway and a deaf woman from Brazil respectively:

Many persons with deafblindness are dependent on an interpreter-guide....Especially when working from home...the pandemic increases the isolation and lack of mobility persons with deafblindness already experience.

I am deaf and communicate through speech and lip reading. With the obligatory use of masks, my communication is greatly affected.

As representative organisations of persons with disabilities, OPDs can only contribute to Covid-19-related decision-making processes when the provisions of accessibility measures are ensured so their staff and members can access relevant information and work and communicate on an equal basis with others. The issues in access to information and communication were the first barriers addressed by the IDA. In the Accessibility Campaign, IDA and the International Disability and Development Consortium (IDDC) urged the UN system to make all public information and (digital) communications accessible. In their open letters to the UN Secretary-General, the UN High Commissioner for Refugees, the UN Population Fund, and WHO, the organisations emphasised that “equal access to information and communication” is a principle and right recognised under the UNCRPD (see, e.g., IDA & IDDC, 2020). For instance, the accessibility provisions should include the following measures on public briefings and webinars delivered by the UN and its agencies by “using radio channels to reach out to people in the most remote areas, providing captioning, International Sign interpretation, plain language” and ensuring the information is easily understandable by avoiding jargon and speaking too quickly (IDA & IDDC, 2020). IDA also attempted to influence the high-level UN bodies to pressure the member states to implement their international obligations and commitments. For instance, the UN was requested to “use all appropriate means” to urge “Member States to immediately ensure access to essential Covid-19 information and adopt a timebound plan to make all public information and communication accessible for all persons with disabilities” (IDA & IDDC, 2020, p. 2).

Similar to Rother's (2022) findings, IDA's research found that the pandemic brought new opportunities for persons with disabilities to participate in society, as many OPDs conducted their activities and services through online platforms. This trend was also observed in human rights governance and decision-making processes among UN bodies (International Service for Human Rights, 2022). However, it exposed the issue of the digital divide between disability communities in different economic and development situations, as some people with disabilities had no adequate access to the internet, phones, and other technologies (DRM, 2020). IDA's survey further revealed that those who could not afford or access the internet and other communication technologies were excluded from keeping in touch with OPDs (IDA, 2021a). The organisation reminded governments to implement their obligations under the UNCRPD to “ensure that persons with disabilities have access to digital technologies that enhance their involvement with OPDs” (p. 50).

### 5.2.2. Disability-Related Discrimination and Exclusion

The second barrier arises from discrimination towards persons with disabilities, including measures that have had a discriminatory impact on persons with disabilities. This was especially evident in the development and

practice of Covid-19 treatment and healthcare policy, such as the triage guidelines in many countries that had explicitly or implicitly instructed health workers to decide treatment based on one's disability. This is indicated in the following excerpt from the international survey that IDA coordinated (cited in DRM, 2020, pp. 41–42):

The survey received a testimony about a Canadian child with autism who was denied a test for Covid-19 “because the attending physician deemed him too difficult to assess. He had all the symptoms of Covid-19 but was refused confirmation.”

A representative of an OPD in the United Kingdom said: “Do not resuscitate notices...were placed on people with no consultation, especially older persons and persons with learning disabilities.”

In its initial Ten Recommendations, IDA (2020a) pointed out that persons with disabilities would be excluded from the policymaking of Covid-19 response if authorities were not aware of how the pandemic measures could “disproportionally impact” them. In the End-Discrimination Campaign, IDA and partner NGOs emphasised that states should comply with their legal obligations and the principle of non-discrimination in their Covid-19 responses and its connection to existing rights under the international human rights framework, such as the right to life, health, education, free information, and an adequate standard of living (Equal Rights Trust et al., 2020). In this process, states should consult with OPDs to assess the impact of their policy response to the pandemic on the ground, such as triage protocols and education policy (IDA, 2020a, 2020b). At this stage, IDA advocated on a global scale with a particular focus on the UN bodies and agencies that had issued numerous policy guidelines to coordinate the global Covid-19 early preparedness, response, and recovery plans. In the later Access to Vaccination Campaign, the main focus was diverted to national stakeholders and the general public. In its open letter, IDA and IDDC (2021) reiterated that persons with disabilities were often left behind in Covid-19 mitigation and response policies and called for the prioritised inclusion of persons with disabilities in relevant vaccination rollout policy and practice. The Ten Recommendations also highlighted the role of OPDs in advocating for a disability-inclusive response to the Covid-19 crisis and encouraged them to “proactively” reach out to all relevant local and national authorities. Accordingly, IDA introduced capacity-building activities for local and national advocacy, as illustrated in the next subsection.

### 5.2.3. Lack of Capacity

The third barrier is the lack of OPD capacity to participate in public decision-making dealing with Covid-19. OPDs encountered difficulties in terms of funding and staff shortages to carry on their advocacy work (IDA, 2021a). Under lockdown measures, OPDs in many African countries were temporarily closed and could not coordinate or carry out their normal activities (Stakeholder Group of Persons with Disabilities for Sustainable Development [SGPWD], 2020). Another contributing factor to these shortages was that OPDs had to shift their focus on providing services to disability communities when public services were absent (DRM, 2020). According to IDA's 2021 survey, 41 percent of respondents (600) received at least one type of service from their local OPDs, such as accessible information on Covid-19, food and/or other essential items, health or social care information, support for mental health, and employment advice. Still, OPDs are sometimes not equipped with sufficient knowledge or resources to support or advocate for particular groups of disabled people (e.g., particular types of impairments or conditions, or those with intersectional

backgrounds) in the disability communities they represent. For instance, this is indicated in the following excerpt from IDA's survey:

“OPDs are more supportive of those with visible disabilities, and they have limited knowledge of how to support those of us with invisible disabilities....Our OPDs do not appear to be aware of the needs of Maori”—Indigenous woman with a psychosocial disability, New Zealand. (IDA, 2021a, p. 50)

IDA has launched several activities to build the capacity of OPDs for advocacy during the pandemic. A cross-cutting theme in IDA's campaigns and advocacy is the importance of the participation of OPDs in the process of making, implementing, and monitoring Covid-19-related policies. From the outset, IDA outlined three working areas where national, regional, and international OPDs can contribute to public decision-making processes through advocacy, including awareness-raising, offering technical assistance on specific measures such as accessibility provisions, and contributing to data collection and analysis (IDA, 2020a, 2020c; SGPWD, 2020). Simultaneously, all IDA campaign messages have reminded and urged international organisations and states to involve and consult with OPDs to ensure their meaningful participation in Covid-19-related decision-making processes in alignment with the UNCRPD and other policies. Furthermore, IDA has facilitated international, regional, national, and local advocacy efforts through coordination, resource-sharing, and capacity-building events. Webinars at regional and international levels were organised to offer training on advocacy strategies based on the international human rights framework. The wide use of media was highlighted throughout the IDA campaigns, and social media toolkits with messages and picture templates for mainstream social media platforms were provided. For instance, in the Access to Vaccination Campaign, a detailed toolkit was published with step-by-step guidelines on running national and local advocacy concerning Covid-19 vaccination policy for persons with disabilities (IDA, 2021b). The toolkit provides instructions on how to identify targets and partners and influence authorities in a country's vaccination policy planning, revision, and practice, as shown in the following excerpt (IDA, 2021b, pp. 2–3):

Advocacy targets are different in different countries: in some countries a specific body under the Presidency is governing national action against Covid-19, in other countries it remains under the Ministry of Health.

Identify advocacy partners including organizations of persons with disabilities, NGOs working on disability, access to health or other groups campaigning for equity and inclusion in vaccination in your country. It is very crucial to avoid duplication so speak to each other and coordinate.

[On recommendations for advocacy meeting with authorities] Try to leave the meeting with some action points even if it is just planning another meeting; offer to support their measures by providing further information or joining potential meetings with other decision-makers.

#### 5.2.4. Lack of Data

Persons with disabilities were often not included in Covid-19-related data collection and analysis at the national and UN levels. This created a fourth barrier to the participation of OPDs in public decision-making processes, such as in the implementation and monitoring of Covid-19 response and recovery policies, which

requires reliable data. This data-related barrier was highlighted in the Rebuilding an Inclusive Future for All Campaign, which was carried out during the 2020 High-Level Political Forum on Sustainable Development. IDA and its partner organisations participated in the meetings and sessions of the Forum through NGO side events, written submissions, and oral statements (SGPWD, 2020). Side or parallel events refer to activities organised and attended by UN stakeholders, such as meetings, presentations, and discussions, that focus on issues relevant to the work of a specific UN body or session but are held outside of the formal session agenda. The Rebuilding an Inclusive Future for All Campaign placed IDA's Accessibility Campaign and End-Discrimination Campaign into the international development and SDGs framework, calling for actions with regard to disability inclusion in broader and future emergency policy, including the monitoring of Covid-19 response and recovery practice. A survey by IDA and partners revealed the issues of lack of disability-related data or access to such data on the national level (SGPWD, 2020). Based on this finding, IDA urged international and national stakeholders to increase disability data collection in future policymaking on emergency response and recovery, as well as draw their attention to relevant data and information collected by OPDs and other NGOs in their surveys.

### ***5.3. IDA in the UN Decision-Making Processes and the Reactions Received***

In contrast to previous studies on the limited participation of civil society organisations in Covid-19 response in local and national governance (Sahoo et al., 2023; Sayarifard et al., 2022), contributions from IDA on the international policymaking during the pandemic were welcomed and acknowledged by the UN system and among OPD and NGO peers. IDDC's 2021 survey, which focuses on the experiences and challenges faced by civil society organisations in the Global South during the pandemic, indicates that IDA and its partners played a crucial role in supporting the advocacy efforts of these organisations for a disability-inclusive Covid-19 response at both UN and local levels, as highlighted by NGO respondents (IDDC, 2021, p. 61):

Coordinated advocacy efforts, such as the IDA/IDDC efforts seemed to have a wider impact on UN systems and responses. Awareness was also increased at remote UN conference.

Case studies collected by IDA were really impressive and thought provoking; their accessibility guidelines were also very useful.

IDA's impact on raising awareness of disability-inclusive Covid-19 policy at the UN level is evident in the written responses IDA and IDDC received from the UN Secretary-General, WHO, and other agencies (see, e.g., UN Secretary-General, 2020). The UN bodies commended the organisations' continuous involvement and contribution to the Covid-19 response policy and indicated their corresponding follow-up actions. Several of IDA's advocacy and toolkits were also listed on the UN website, as with other UN resources, advice, and guidelines for disability-inclusive Covid-19 policy (UNDESA, 2023).

IDA has also directly participated in official policymaking processes related to international Covid-19 response and recovery policies in the context of international development and SDGs through its involvement in the UNPRPD and the SGPWD. IDA is also the only OPD member organisation of the UNPRPD and its board. Along with the IDDC, the two organisations participated in a UN joint project to promote disability inclusion in Covid-19-related policies in 27 countries between 2020 to 2021 (UNPRPD, 2022). IDDC is a civil society organisation group working on promoting disability rights and inclusion in international development and

humanitarian action. IDA and its member organisations provided technical expertise in the development and implementation of Covid-19 policy documents and guidelines issued by UN bodies and agencies, including UNESCO, UNICEF, the International Labor Organization, and WHO. According to the 2022 UNPRPD report, UN organisations, such as the OHCHR, reported that their engagement in the disability networks through IDA and IDDC, such as seeking consultancy, strengthened the implementation of global programmes supporting Covid-19 response and recovery. Such engagements also created “prospective opportunities for disability inclusivity” in Covid-19-related social and economic recovery plans at country levels (UNPRPD, 2022, p. 67).

## 6. Discussion: Creating Participation Spaces and Reflecting on Hostilities

The results of the document analysis on IDA's international advocacy during the Covid-19 pandemic show that this OPD network has attempted to influence global and national decision-making processes on the pandemic preparedness, response, and recovery measures, as well as relevant practices through a range of transnational public participation activities.

IDA first highlighted the situation that persons with disabilities and their representative organisations did not participate in the Covid-19-related policy and practice on the ground. It further identified the four main barriers that prevented persons with disabilities and OPDs from participating in Covid-19-related decision-making, namely: lack of access to information, communication, and physical environments; disability-related discrimination and exclusion; lack of capacity of OPDs to engage in decision-making; and lack of disability-related data. Following the previous findings, the first two barriers indicate that persons with disabilities and OPDs face additional barriers to participation relative to other individuals and civil society organisations (McVeigh et al., 2021). Barriers experienced by people with disabilities directly affect their ability to participate in decision-making processes: If they cannot communicate with each other and policymakers, they cannot make decisions relating to their lives or receive information on policies. It seems that these adverse impacts at individual levels did not greatly hinder the work of others in similar situations (Kövé, 2021; Marston et al., 2020; Rajan et al., 2021; Sayarifard et al., 2022). The last two barriers pertain to a lack of capacity or data, highlighting challenges that hinder OPDs in particular from contributing to public decision-making processes and organising collective actions.

Three interlinked strategies were used in IDA's participation and advocacy to influence international disability-inclusive Covid-19 policy. The first strategy is the consistent use of human rights language in advocacy in contrast to the approach taken by many UN bodies in their policy and information outputs on Covid-19 and disability rights (Lewis, 2020). This is evidenced in IDA's open letters, publications, and capacity-building activities cited in the last section, which have made explicit references to human rights norms. The international normative framework, in particular the UNCRPD, provides the foundation for IDA's advocacy, which allows it to identify concrete barriers and connect them to existing legal and political obligations made by supranational organisations, states, and other stakeholders. Articles 4(3) and 33(3) of the UNCRPD provide the legal basis for creating invited spaces for the participation of OPDs in public decision-making processes, namely the obligation to consult, which will be elaborated below.

The second strategy is building alliances with other OPDs and NGOs. In addition to the IDDC, its frequent and main partner in public campaigns and UN engagement, IDA worked with a range of human rights NGOs advocating for the rights of, among others, women, children, refugees, and sexual and gender minorities

(see, e.g., Equal Rights Trust et al., 2020). This is in line with IDA's first strategy, which focuses on human rights issues. The third strategy is to employ multiple activities simultaneously with the aim of supporting IDA's participation in the UN decision-making processes. As demonstrated in the last subsection, each campaign launched different advocacy activities tailored to different audiences. Survey findings were fed into its international advocacy and contributed to IDA's participation in the UN system, providing a factual basis for its consultancy, awareness-raising efforts, and policy recommendations. This third strategy is also built on the second strategy since many of IDA's activities (e.g., surveys) involved support and contributions from and coordination with other NGOs and stakeholders. The three strategies reflect IDA's two-way approach when participating in international policymaking processes related to Covid-19: amplifying the voice of persons with disabilities and the movement from all over the world to the UN (bottom-up) as well as relaying UN policies and principles to persons with disabilities on the ground (top-down).

IDA has participated in the international policymaking processes through both "invited" and "invented" spaces (Rother, 2022). The former was achieved through participation in UN official decision-making processes, while the latter was created through public campaigns where IDA coordinated or collaborated with peers in the international disability movement and its allies. Invited spaces in the international policymaking processes remained open to IDA during the global pandemic. Unlike civil society organisations on the national and local levels (Kövér, 2021; Sayarifard et al., 2022), the participation of IDA in high-level formal procedures was not blocked or ignored in the UN system. The outcomes of IDA's consultancy, research, and awareness-raising campaigns corroborate with previous research findings (Sahoo et al., 2023) that show the crucial role of OPDs in the development and delivery of context-relevant responses to the global pandemic since they have first-hand knowledge on the needs of disability communities. However, participation was not always meaningful or inclusive—contrary to the principles envisaged in the UNCRPD and other international policies—due to barriers in accessibility provisions and discrimination encountered by certain groups of persons with disabilities.

Invented spaces in the international policymaking processes were created by IDA during the pandemic. Similar to Rother's findings, new spaces, such as virtual participation, were created for all civil society, which became both an opportunity and a challenge for OPDs, such as creating additional barriers to the accessibility of information and communication technologies. Through various invented spaces such as open letters, publications, NGO side events, webinars, and social media campaigns, IDA pressured the UN system, national governments, and other stakeholders to remove existing barriers in order to include all persons with disabilities and OPDs in Covid-19-related policymaking, whose voices were often excluded on the ground or in new participation spaces. By engaging in both invented and invited spaces, IDA facilitated the "travel" of ideas from invented spaces into invited spaces, aiming to influence policy changes related to the public participation of persons with disabilities on the ground. This finding reflects those of Rother (2022), who notes a similar strategy in the participation of civil society organisations within global migration governance. Furthermore, IDA seeks to secure permanent invited spaces for disability communities in the broader framework of risk management on human rights and humanitarian emergencies and future emergency policymaking.

Reflecting on the discussion introduced at the beginning of this article regarding the relationship between indirect hostilities and limited, circumscribed, and selective participation, we find that it resonates with the findings of the current study on the relationship between the four barriers and participation of persons with



disabilities and OPDs in Covid-19 decision-making processes. The participation of persons with disabilities is clearly required and supported in international human rights and development policies and governance. None of the four barriers discussed in this study were intentionally placed by decision-makers to directly prevent their participation during the global pandemic. However, these barriers hindered the individual or collective participation of persons with disabilities in national and international Covid-19 policymaking processes in a meaningful and inclusive manner. Their lack of participation also highlighted pre-existing inequalities and barriers faced by disability communities in their daily lives, including underrepresentation in public participation, similar to the experience of other marginalised groups (IDA, 2021a; Perry et al., 2020; Rother, 2022).

## 7. Conclusion

This article has examined the barriers to participation faced by persons with disabilities and the response from IDA, a prominent international network of organisations of persons with disabilities representing the international disability movement. Our findings align with existing research that reveals the exclusion of civil society organisations by many national governments despite their ability to engage communities during the global pandemic. The disability rights movement experienced barriers regarding the lack of capacity or data and additional barriers at the individual level in terms of a lack of accessibility and disability-related discrimination, which hindered its participation in the development and practice of Covid-19 policies. IDA mobilised “invited” spaces and creating “invented” spaces for public participation during the pandemic, aiming to remove these barriers. IDA has also strategically utilised international human rights and development frameworks, as well as NGO allies, to prompt its participation in both types of spaces according to its goal of promoting a “disability-inclusive response” to the global pandemic and future decision-making processes related to emergencies (IDA, 2020a). Discussing and applying the conceptualisation of participation spaces and the consequences of indirect hostilities to participation, findings in this study have broader implications for research on lack or limited public participation in situations of risks and emergencies in the context of disability and human rights studies, including other marginalised groups in societies. This study provides insights into understanding the connections between individual and collective human rights violations and the lack of or limited public participation of certain groups in society. We examined the strategies and experiences of a prominent OPD network operating in highly formalised institutional governance settings in international policymaking. Future studies should extend this examination and comparison to include OPDs operating in less formalised settings. It is beyond our study scope to address the impact of a global social movement being represented by one high-level organisation, albeit one with an extensive network. This raises questions about representation and accountability and how they relate to participation within the movement, which are worthy of future examination.

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## About the Authors



**Hanxu Liu** (PhD) is a lecturer and researcher in the Health, Ethics, and Society Department at Maastricht University. Her research focuses on the impact of global disability movements in the implementation and monitoring of international human rights instruments at local, regional, and global levels. She uses socio-legal research methodology, applying legal and theoretical frameworks alongside empirical research to explore the interactions between law, social movements, and human rights practices.



**Claudia Coveney** (PhD) is a lecturer in disability studies and policy in the School of Sociology and Social Policy at the University of Leeds. Her research examines opportunities for social movement organisations, particularly disabled people's organisations and their allies to mobilise and influence decision-making as institutions of governance develop new structures.

# Self-Organised Practices of Social Participation; or How Individualisation is Collectively Contested in the Raval

Olaf Tietje 

Department of Sociology, LMU Munich, Germany

**Correspondence:** Olaf Tietje ([olaf.tietje@lmu.de](mailto:olaf.tietje@lmu.de))

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## Abstract

In this article, I focus on current developments in the Raval district of the Spanish metropolis of Barcelona and show how social participation can be made possible despite hostility. Social participation is the opportunity for subjects to take part in society and, in this way, to experience “belonging to society.” “Belonging to a society” means experiencing both active and passive opportunities to shape and use socially founded and politically constituted community relationships and infrastructures. The example of the Raval shows how neighbours can be activated as a collective through self-organised practices of social participation. In the context of a welfare state in transformation, social participation is partly being transferred from the state to civil society actors. Focusing on the issues of housing, security, and care, this article shows how, on the one hand, this transferring of responsibility contradicts individualisation and creates something in common. On this basis, the residents can find collective answers to individualised problems and improve social participation. On the other hand, it shifts the weight of social responsibility unto civil society, which means that social participation is no longer guaranteed by the state and, as in the case of the Raval, becomes dependent on more or less randomly developed structures in the social environment.

## Keywords

Barcelona; collectivising; hostility; neighbourhood; self-organisation; social environment; social participation; Spain

## 1. Introduction

The population of Barcelona, as in the whole of Spain, was heavily affected by the financial crisis of 2007–2008 and the austere regulations of the European Union, such as cuts in spending on the welfare

state (Colau & Alemany, 2012). As a result, a variety of crisis management structures, mostly developed by civil society, emerged that attempted to compensate for the effects of this crisis and for how they were handled by the state (PAH Barcelona, 2016; Suarez, 2014). For example, one direct effect of the financial crisis was very high unemployment. As a result of job losses, many people in Spain were no longer able to pay off the mortgages on their homes. This led to an enormous increase in the number of evictions, with many people losing their homes. The protests against evictions gave rise to the Plataforma para los Afectados por la Hipoteca (PAH, a self-organised initiative working against the eviction of people and in favour of the right to housing). This platform became a counselling body that supports people in negotiating mortgages with the banks and preventing evictions and initiated a row of social work that went far beyond these tasks (PAH Barcelona, 2016). This and other examples constituted what can be called a civically organised participation infrastructure.

One aspect of these civically organised infrastructures is the neighbourhood trade unions, as the example of the Raval Housing Union (Sindicat d'Habitatge del Raval) used in this article. In contrast, the ongoing transformations of the welfare state are geared towards a further *individualisation* (Bauman, 2001) of *social participation* (Kreimeyer, 2017; Serrano Pascual et al., 2019). Consequently, this situation can be characterised as *hostile* to participation (e.g., Edwards & Maxwell, 2023; Morgan, 2023; Redert, 2024). Against this background, this article looks at how the residents of the Raval organise social participation themselves and, in this way, not only create participation infrastructures but also consolidate them, thereby contradicting social individualisation.

Social participation is understood by various authors as a counter-concept to exclusion (e.g., de Miguel-Luken & García-Faroldi, 2021; Kronauer, 2013; Morgan, 2023; Wansing, 2005). In this respect, social participation can be used to describe what no members of society should be excluded from (Niess, 2016, p. 69). Belonging to a society is subject to legal regulations (e.g., Koch et al., 2009, p. 273), but it is also framed by normative invocations (Bartolini, 2021, p. 63). Understood as a general abstract societal goal, social participation is a concept that can be used to work towards social cohesion (e.g., Berger-Schmitt, 2000; de Castro Sanz, 2013; Jaffe & Quark, 2006; Laparra Navarro, 2010). In this way, social cohesion becomes a process that takes place in local social environments, fed by acts of belonging and participation as well as the possibility of achieving self-imposed life and status goals, i.e., social participation (Kersten et al., 2022, p. 19). In this respect, social participation is an elementary component of social cohesion, which is closely intertwined with ideas of community, reciprocity, and acts of solidarity. Thus, social participation and the practices that enable it are the basis for the democratic constitution of societies: Solidarity as a unifying value creates a social obligation that enables participatory practices of shaping society and achieving respect for a common coexistence (Jaffe & Quark, 2006, p. 210; Keupp, 2010, p. 23).

I understand social participation as the opportunity for subjects to take part in society and thus experience belonging to society. "Belonging to a society" means active opportunities to shape and passive opportunities to use socially founded and politically constituted community relationships and infrastructures. Against this background, I understand hostility to social participation as something that directly and indirectly hinders access to societal relationships and infrastructures.

Hostility to social participation consists in particular of the *individualisation* of opportunities to participate. As Castel (2005), among others, shows, the transformation of welfare states is a decisive factor in this regard.



In Spain, the transformation of the welfare state began in the 1980s (Albarracín et al., 2000). In general terms, the development of the Spanish welfare state was shaped by late social legislation at the beginning of the twentieth century and limited economic liberalisation under Franco and the democratisation of the post-authoritarian social system. It is currently a post-authoritarian system with mixed public–private components (Enderlein, 1999, p. 397; Lessenich, 2008, pp. 235–240). During the initial years of its existence and against the backdrop of the economic miracle of the 1960s, this system placed economic efficiency before social democratisation. This resulted in the maintenance of clientelism and traditional inequalities. Despite advancements in women’s rights, family networks have remained crucial for social security (Koller-Tejeiro, 1988, p. 474; León & Migliavacca, 2013, pp. 27–28). The fragmentation of the welfare state system was a direct result of the flexibility of labour rights (Pavolini et al., 2015, pp. 66–67). Subsequently, the European austerity policies after 2007–2008 affected the system through employment flexibility and by linking social benefits to employment. The Spanish welfare state is criticised for its familiar-conservative model, which is particularly harmful to women, single mothers, families with young children, immigrants, and the elderly, especially during economic crises (Ibáñez & León, 2014, p. 294; Pavolini et al., 2015, p. 71). Among other things, this model implies a *decollectivisation of society*, which I understand as the tendency towards individualisation coupled with the transfer of welfare state’s responsibilities unto citizens (Castel, 2011, p. 171).

Individualisation so defined means there’s a hostility to social participation as opportunities to participate are not (or no longer) guaranteed by the state—or are so to a lesser degree than before. The realisation of the collective guarantee of participation in society is shifted to the individuals themselves. This also means that obstacles that stand in the way of participation become individual problems. Therefore, the individualisation of participation opportunities also means that the respective difficulties are individualised. This is particularly visible because the transformation of the Spanish welfare state following the global financial crisis has unequivocally resulted in increased social inequality (Gómez Bengoechea & Quan, 2020). The Spanish state transferred responsibility for parts of the welfare state infrastructure to local administrations and civil society organisations (Del Pino & Pavolini, 2015). This becomes clear, for example, at the level of social work and counselling, which were more strongly organised on a municipal basis before the European financial crisis. With the austerity measures, however, these services have been largely privatised and transferred to civil society organisations (Caravaca Sánchez et al., 2022). The process of transferring state infrastructures to civil society, which is generally described as neoliberal, fundamentally alters the logic through which states govern (Dean, 2014). Rather than retreating, the state modifies the logic and practices of its interventions. The resulting individualisation gives rise to new forms of subjectification (Lessenich, 2008).

In this sense, the state’s abdication of responsibility for the community creates a crisis of social participation and, as a result, of social cohesion in societies (Kersten et al., 2022, p. 22). The transfer of responsibilities to civil society is linked to state incentive structures and normative affective debates as to who should participate in which areas of society or have access to which resources (Heinze et al., 2021, p. 82; Tietje, 2023a, § 34). While many studies in this context focus primarily on participation in the labour market as the basis for participation in society (e.g., Campos Vázquez & Chiguil Rojas, 2024; Koch et al., 2009; Naveed et al., 2024), some studies also refer to alternative participation structures such as protests or social movements (e.g., Carbonero Gamundí & Gómez Garrido, 2023; Gutiérrez-Sastre et al., 2024; Serrano Pascual et al., 2019, p. 228). Many studies on the enabling of social participation focus on rights and laws



(e.g., Rohrmann, 2008; Rudolf, 2017) and try to explain the exclusion of a specific, often marginalised group (e.g., Rodriguez & Giametta, 2024; Wansing, 2005).

Relying on the example of the neighbourhood of the Raval, a district of Barcelona, I will focus on self-organised participation practices. Related to studies on social participation investigating protests and movements (e.g., Gutiérrez-Sastre et al., 2024) and those looking at neighbourhood networks (e.g., Barañano Cid et al., 2023a; Lubbers, 2021), I will show how social participation can become possible in hostile situations and how neighbours establish at least temporary infrastructures of participation through self-organised practices. Those collective responses to individualised problems, I will conclude, carry a transformative potential. For this purpose, I will first describe my understanding of the hostility of the situation and expand my reading of social participation (Section 2). Based on my empirical findings since 2021, this will be followed by a short introduction to the neighbourhood of El Raval (Section 3). Building on this, I will briefly present my methodical approach (Section 4). After this, I'll show my empirical findings on how the inhabitants of the Raval establish self-organised practices of social participation amidst hostility (Section 5) and finally end with a brief overview of results (Section 6).

## 2. Hostility to Social Participation

I define social participation as the opportunity for subjects to take part in society and thus experience belonging to society. This means, in concrete terms, focusing on whether and how people can participate in the areas of coexistence that are fundamental to a decent life: clean air, safe housing, adequate food supplies, basic amenities, childcare, access to education, communication infrastructure, healthcare and local public transport (Rao & Min, 2018, p. 229). Concerning the distribution of such goods, it becomes clear that social participation is not a social precondition but must be fought for. Demands for equal participation by different social actors mark the path to democracy (Rudolf, 2017, p. 13). Hostilities toward participation operate in different ways, but for the context of this article, it is—first—particularly relevant to look at the neoliberalisation of the welfare state. Above all, neoliberalisation leads to the individualisation of participation opportunities. Secondly, countering this hostility to social participation appears to occur above all in the social environment. This is where renewed collectivisation of responses to social problems can take place. However, this collectivisation by civil society actors can mean a responsabilisation of civil society. In order to better link these considerations with my further explanations, I will now unpack these points in detail.

First, the neoliberalisation of the welfare state shifts opportunities for social participation primarily to the individual level. While previously state guarantees were an expression of state collectivisation of welfare, these are now largely linked to individual wage labour performance. This, for example, excludes people under the age of 25 from unemployment benefits, and all others must have worked for at least 360 days in six years to gain access. In this way, public security is transformed into social insecurity (Castel, 2005). The people who are most affected by this insecurity are those who have less or no economic, cultural, or social capital and are therefore dependent on collective social security in order to be able to participate in society (Castel, 2005, p. 65). The privatisation of social security, in turn, severely restricts access to participation. The privatisation of public spaces and services also plays a particularly important role in Barcelona (Mansilla López, 2016), as I will show below.

At the onset of the austere treatment of the financial crisis, after 2007–2008, activists from protest movements succeeded in developing their own strategies for dealing with the exacerbation of social inequality (Beltran, 2024). A famous example is the above-mentioned PAH, which succeeded in developing collectivised advisory strategies in which members were relatively successful in resisting evictions (PAH Barcelona, 2016). The PAH has changed over time and lost relevance in many places in Spain. Currently, in some areas like Valencia and Barcelona, its strategies are being followed by the creation of neighbourhood unions in which activists from the neighbourhoods come together and jointly develop practices for enabling participation (Rossini et al., 2023). These neighbourhood unions place a special focus on forms of community organising—as examples from some neighbourhoods in London show (Bader, 2020, p. 191).

The shift in responsibility for social participation opportunities from the collective to the individual level acts as a strategic activation of civil society (Lessenich, 2008). This responsabilisation of civil society accentuates the level of community responsibility in addition to both personal and family responsibility. Social participation is developed through renewed collectivisation organised by civil society at the neighbourhood level (Heinze et al., 2021, p. 73). This responsabilisation, partly initiated and partly supported by the state government, thus refers to the responsabilisation of civil society actors.

For example, in 2012, following the financial crisis of 2007–2008 in Spain, healthcare was linked by Royal Decree directly to social security (RDL 16/2012). This had effects on those among the population living in Spain without a work permit or who were not registered in the social security system. Previously, people living in Spain could simply apply for a health insurance card (*tarjeta sanitaria*) and use state healthcare. From then on, because of the austerity measures, health insurance was linked to social security, and it was made much more difficult for people working in informal employment to participate.

Secondly, it can therefore be stated that hostility can be aimed directly and indirectly against participation and can create obstacles to participation both intentionally and unintentionally (see Zvonareva & Egger, 2025). In Spain, social participation has especially been met with hostility since the financial crisis. Conditions in the labour market have improved somewhat through state subsidisation of banks in financial difficulties, but the neoliberalised social security system has created difficult conditions for all people in Spain who live in the lower-income brackets. My reflections on the neoliberalisation of the welfare state led to the relevance of the social environment and new forms of collectivisation. Although everyone in Spain still has the right to healthcare, regardless of their residence status (RDL 7/2108), they must still prove that they have been employed for 90 days to be able to participate in healthcare and not only have access to emergency care. Various initiatives and protest movements tried to achieve access for people in informal employment without a *tarjeta sanitaria* (e.g., Cruz Roja, 2024; Huke & Tietje, 2014, pp. 540–542). The result was that their participation-generating activities led to a reform of the law and in 2024 to granting healthcare for everybody living in Spain (“Cualquier residente en España,” 2024; Revision of RDL 16/2003). In terms of how Spanish society sees itself, it becomes clear that there is a great lack of interest among those people who are not already part of the social security system. While it may not have been the explicit aim of the reforms to exclude migrants from healthcare, this was the consequence.

Until this reform in the first half of 2024, illegalised immigrants in Spain were dependent on support from their social environment and networks if they needed medication or other medical care (e.g., Huke & Tietje, 2014, p. 542). Such support from people’s immediate social environment plays an important role in a wide

variety of aspects of participation, especially when state infrastructure—as in the above-mentioned example—is not guaranteed (e.g., Bartolini, 2021, pp. 134–136). Neighbourhood networks, family, and friendship relationships often form the basis for practices of enabling participation and can, under certain circumstances, gain non-institutionalised perpetuation in relationships of solidarity. Creating such relationships can become a very important aspect. Within a social environment, these relationships become what, in relation to the question posed at the beginning, makes it possible to work out collective answers to individual problems.

As I will show below, the interactions in the social environment become particularly relevant. Social environments include the immediate physical surroundings, social relationships, and cultural milieus within which people interact and function (Barnett & Casper, 2001, p. 465; Zastrow et al., 2019, p. 3). These environments can produce infrastructures within which new opportunities for social participation can be developed (Barañano & Santiago, 2023, p. 2). Thus, with the concept of the social environment, I refer to the networks, infrastructures and relationships of the subjects that come into play at the local level. In the social environment, collective forms of dealing with the problems of social participation can be developed. Those forms can also point in the direction of social transformations (e.g., Barañano Cid et al., 2023b; Serrano Pascual et al., 2019).

Against this background, it becomes obvious—thirdly—that social participation as such is linked to the debates about exclusion (Bartelheimer et al., 2020, p. 43). Discourses, laws, and norms in societies shape the frameworks that make the unequal treatment of individuals or groups legitimate. These ideas and frameworks are created and implemented by people and can therefore also be changed by them. In conjunction with the above-mentioned transformation of state logic as a neoliberalisation of social security policies, a transfer of responsibility to citizens is taking place. This responsabilisation of civil society and the activation of civic voluntary work make the neoliberal enlistment of civil society (Lessenich, 2008, p. 16; Serrano Pascual et al., 2019, p. 229; Tietje, 2021, p. 136). Social participation as a value in and of itself enables social security tasks to be transferred to civil society. In this way, not only are the possibilities for participation neoliberalised but also its practices, which in turn has a direct impact on those professions, such as social work, that are historically responsible for organising social participation (Bettinger, 2021, p. 59). With these three aspects of hostilities toward social participation, the article will now turn to the neighbourhood of the Raval.

### 3. The Neighbourhood of El Raval

Barcelona is a large city in northern Spain. The Raval neighbourhood is a degraded historic centre next to the harbour that is now in the process of urban rehabilitation and has become a touristic hotspot and home to the famous Rambla (a 1.2-kilometre-long promenade in the centre of Barcelona). The neighbourhood is inhabited by a considerable number of immigrants from the global south. At the heart of this neighbourhood is the district popularly called “Chinatown,” an area with a long history of street sex work (Aisa & Vidal, 2006, p. 325; Benito, 2000, p. 344). The district was subject to major restructuring, particularly in the mid-1990s, which, however, did not improve the quality of life of the district’s residents as much as it made it more attractive to tourists (Scarnato, 2014, p. 16). With the construction of the new Rambla, the expansion of the port, and the establishment of several large museums in the district, the number of tourists increased continuously (Rius-Ulldemolins, 2014, p. 7).

Since then, the neighbourhood of Raval in Barcelona has undergone an ambiguous development characterised by contrasts and change (Aisa & Vidal, 2006). Once notorious for its crime and neglect, the area has transformed into a cultural and touristic centre in recent decades (Degen, 2003). This transformation has been propelled by several factors, including government investments in urban renewal projects, the establishment of cultural institutions such as the Museum of Contemporary Art (MACBA) and the Centre of Contemporary Culture of Barcelona (CCCB), as well as the rise of alternative art and music scenes, and the influx of young, creative residents (Rius-Ulldemolins & Klein, 2022).

In spite of these changes, and despite the shift of Barcelona's local government to the left after 2015 (Blanco et al., 2020), the Raval remains a place of social challenges. The neighbourhood continues to attract a diverse mix of locals, newcomers, and tourists. The Raval has faced challenges related to social inequality and marginalisation. The neighbourhood has a history of stigmatisation and marginalisation of its poorer, mostly immigrated inhabitants, which has manifested in various forms of hostility and discrimination. This hostility often stems from socio-economic factors, such as the perception of the Raval as a disadvantaged area associated with poverty, crime, and social problems (Rius-Ulldemolins & Klein, 2022, p. 6). The inhabitants of the Raval face various forms of exclusion, such as discrimination in access to housing, employment, and public services, thus exacerbating their social and economic marginalisation (Scarnato, 2014, p. 12). Gentrification and rising property prices have further marginalised low-income residents, leading to their displacement and the loss of affordable housing options (Sequera & Nofre, 2018, p. 94; Suarez, 2014, p. 86). This hostile environment for the inhabitants underscores the ongoing struggle for social justice and equity within the neighbourhood, highlighting the need for inclusive urban development policies that prioritise the needs of all residents, regardless of their socio-economic status (Sequera & Nofre, 2018, pp. 94–95). Even though social housing projects had been implemented in the 1980s, from the beginning of the 2000s onwards, the renewal projects in the district mainly meant rising rental costs for the residents and increased air pollution from the larger ships, especially cruise ships, in the port.

These factors have a particularly strong influence on the living conditions. Due to the historical development of the neighbourhood—its former peripheral place and the direct connection to the port—many people live in the district who have direct experience of migration and/or are racialised due to an attributed migration history (Sargatal Bataller, 2009). The poverty of migrant people in the Raval is often linked to crime and sex work in public discussions and public media (Benito, 2000). Against this background, migrantised people are not only exposed to the exclusive factors already mentioned but must also deal with racist attributions and discrimination (Contreras Hernández, 2019).

#### 4. Methodical Approach

The insights presented in this article are based on a research project (“Social Participation of Migrantised People in the European Union”) on the voluntarisation of practices that enable social participation. The project, supported by postdoctoral funding from the Ludwig Maximilian University of Munich, is in its final stages at the time of writing. In this research, I use an ethnographic approach with participant observations (Lamnek, 2010, pp. 498–500) and semi-monological interviews (Helfferich, 2011, pp. 43–44). I conducted observations and interviews ( $N = 30$  interviews) in the two cities of Barcelona and Hamburg between 2021 and 2023. Interview partners were mostly neighbourhood activists, social workers, and members of small cooperations, clubs, and associations.

At the beginning of the semi-monological interviews, I asked the interviewees to tell their stories regarding my research topic on social participation in a very open way but accompanied by narration provoking questions (Helfferich, 2011, p. 36). These narrative-generating questions were always adapted to the respective interviews and worked as follows in the context of the neighbourhood union: “I am interested in everything that you say led to you becoming active in the neighbourhood. I would like to ask you to tell me how you came to be a member of the Raval neighbourhood union.” The aim of these interviews was therefore to produce episodic stories based on the research question(s). Within the framework of this multi-sited (Marcus, 1995) urban ethnography (Ocejo, 2013), I produced diverse and far-reaching data that point to the focus of this article (for insights into my research in Hamburg see, for example, Tietje, 2023a).

I analysed the anonymised data by making the situational analysis framework (Clarke et al., 2018) fruitful for my research, which is a post-structuralist version of grounded theory. I use the mapping procedures developed by Clarke et al. (2018, pp. 101–103; see also Tietje, 2023b), which I adapted and developed further for this specific analysis, as I explain elsewhere in more detail (Tietje, 2023a). Situational analysis is a research method that enables scientists to analyse with its mapping techniques complex, multidimensional, and closely interwoven social realities (Clarke et al., 2018). The integration of mapping approaches into research serves the empirical and analytical investigation of collective actors and their negotiation of controversial issues.

## 5. Neighbourhood Practices Between Individualisation and Collective Answers

Against the background of my explanations above on social participation and the developments in the Raval district, in this section I will focus on the self-organisation of residents of the district. To this end, I will first focus on hostility to participation and then show how the potential for social participation can be generated through the practices of self-organisation despite such a hostile situation.

### 5.1. *Been Left Alone: The Situation of Hostility*

The development in recent years has enormously increased the attractiveness of the Raval for tourists. However, the fact that the policies that place the attractiveness for tourists on the backs of the people who live in the Raval are being continued is leading to great dissatisfaction. In one interview, an activist of the local association *Sindicat d’Habitatge del Raval* states:

All of the city policies in Barcelona, since 1992, since the Olympics began [were]...a disaster for the neighbourhoods, especially in the centre....All of Barcelona has suffered from it, but here all the policies that have existed in the city since the Olympics until today have gone to great effect, have implemented policies to attract more tourism and large companies to invest here. (*Sindicat d’Habitatge del Raval/activist 01, interview 8 September 2021*)

The neighbourhood unions that have emerged in some parts of the city consist of self-organised structures that work in various areas to promote the participation of people in the respective districts. The *Sindicat d’Habitatge del Raval* is—like other neighbourhood unions in districts of Barcelona (e.g., *Poble-Sec* or *Poblenou*)—an association that provides support for everyone looking for it in the neighbourhood of Raval.

They describe the environment as hostile to social participation. In the interviews I conducted, many activists identified the Olympics and the associated renovations as the starting point for gentrification in the Raval. The renovations are seen as being connected with the deterioration of the living conditions of the local population and make Barcelona look like a city that functions as a model of how economic interests can be asserted in a very hostile and aggressive way against the people living in the neighbourhoods (Delgado, 2017, pp. 12–13). With the election of the left-wing PAH-based mayor Ada Colau in June 2015, many hoped for improvements in the general situation, but these only came very slowly. The legal regulations against the so-called “Airbnbisation” have had little direct impact, especially in the Raval (Sequera & Nofre, 2018, p. 94; see also Blanco et al., 2020; Peña López, 2019):

Very few municipal policies have been at the service of residents. It's ridiculous, even now that in principle a government reigns that was going to change everything....In fact, [it became obvious] that tourism does not bring money because all the big companies extract it and take it away. Now they want to build the Hermitage, the museum here in the port, what service does that provide to the neighbours?...We have seen that the wealth of tourism has gone away, because in neighbourhoods like El Raval almost half of the population is at risk of social exclusion. In the centre of Barcelona, the great tourist capital, and here people don't even have enough to eat. (Sindicat d'Habitatge del Raval/activist 01, interview 8 September 2021)

The activist's disappointment becomes particularly clear against the background that the population of the district was barely or not included in planning considerations and there have been hardly any improvements to participation infrastructure and opportunities. Since the 2015 local elections in Barcelona, for example, there has been a shift towards greater citizen participation in political decision-making, even outside of parliamentary processes (Peña López, 2019). At the level of social participation in everyday life, however, people in the Raval neighbourhood experience this only to a limited extent, which indicates that social participation must be fought for.

At the same time, the cost of living has risen enormously (Solís & Gil, 2024, p. 26), which means additional burdens, especially for the mostly poorer population in the Raval. This has a particularly negative impact on the affordability and quality of life of residents in neighbourhoods with high tourist traffic, such as the Raval. In conjunction with the transformations of the welfare state mentioned above, people with a low or no income are socially decollectivised in this way: Individual social participation can no longer be guaranteed by state infrastructures.

A further dimension becomes visible when we look at the gendering of social participation opportunities. Women in particular are disproportionately affected by poverty, especially when they take on responsibility for children or family members (Barañano Cid et al., 2023b), particularly since the opportunities for using the social security system in neoliberally organised societies are often linked to regular employment (Kronauer, 2013, p. 23). Hostility towards social participation accumulates here and the individualisation of social participation opportunities becomes gendered.

The hostility of the situation for many of the residents in the Raval is further increased by the fact that to be able to offer holiday apartments, many companies try to drive away tenants by increasing rents. If people can no longer pay the rent or mortgage for their apartments, they are forcibly expropriated and thrown out of their



apartments (e.g., Sorando et al., 2023; Suarez, 2014). Childcare and schooling are also complicated under these conditions, which points to the relevance and urgency of close social relationships. Overall, the situation in the Raval is characterised by stark social discrepancies stemming from the developments described above. On the one hand, many tourists cross the district every day, shop and party here, enjoy the sights, and take in the cultural offerings. On the other hand, the people who live in the district and, in a sense, function as a backdrop for the Raval brand in Barcelona (Rius-Ulldemolins & Klein, 2022) cannot afford the district's amenities:

What neighbours of the Raval go to the MACBA? Or what's it for? In a neighbourhood where half of the population is at risk of social exclusion, that they evict them, that everything, you have a museum there with works costing a million euros. Are we crazy? What's the point? What good does that do for the neighbourhood? On the other hand, just the construction of the MACBA, there were houses there, and they tore it all down, kicked out the neighbours and built this mega-structure, here in the middle...Everywhere around MACBA, they raised the prices and ended up expelling all the neighbours who lived in that area. (Sindicat d'Habitatge del Raval/activist 01, interview 8 September 2021)

The gentrification of the Raval is vividly illustrated by the example of the MACBA (Mazorra Rodríguez & López-Gay, 2024, p. 3). Although this is of little interest to the residents of the neighbourhood, their living space was directly restricted by the fact that houses were demolished to build the MACBA, and indirectly as rents have risen due to the presence of the museum in the neighbourhood.

Accordingly, activists in the Raval developed forms of protest against the continuous increase in tourist attractiveness and the further expansion of the district in precisely this direction (Sequera & Nofre, 2018, pp. 95–96), for example, through tourism-attacking graffiti or stencils in popular places in the district, banners hanging from apartments that address real estate speculation or other strategies that diminish the attractiveness of the district for tourists (Geography Field Work, 2005; Oskam, 2019).

Overall, the Raval has become much more attractive to tourists in recent years. This is only associated with a few improvements for the residents of the neighbourhood—such as increased opportunities to find employment in the tourism sector (Solís & Gil, 2024). In recent years, Barcelona's left-wing city government has also implemented very few positive developments for the neighbourhood's residents (Blanco et al., 2020). The overall high increase in the cost of living due to tourism in the city has been combined with an expansion of tourist infrastructure at the expense of both neighbourhood and care infrastructure (Sargatal Bataller, 2009). Coupled with the transformation of the welfare state and the resulting decollectivisation of participation structures (Castel, 2011), the residents of the Raval are largely thrown back on themselves with their problems: they feel left alone.

## **5.2. Collectivising Strategies: Social Participation Amidst Hostility**

In this hostile situation, the residents have developed different ways of working together, opposing individualisation. Following the long history of collective organising in Barcelona (Pera, 2020, p. 3), there is a particular focus on the question of housing, along with rising rents and high mortgage debts:

For example, the Sindicat d'Habitatge del Raval, the vast majority of cases [we are accompanying] are cases of occupation, some of rent payment, and a little of everything, but above all it is occupation.



And yes, people meet there and talk about their problems. (Sindicat d'Habitatge del Raval/activist 02, interview 8 September 2021)

As the activist explains in this interview, the members of the Sindicat d'Habitatge del Raval use old vacant residential buildings and occupy them. In this way, housing is organised for those who urgently need it. The activists here also work with occupation strategies when members are threatened with eviction. Many people are then organised to unite at the affected apartment, and by overcrowding the respective apartment through large numbers of people, they prevent the eviction notice from being handed over and the police from carrying out the eviction (fieldnotes from September 2021). In this way, neighbours fight together in everyday life against direct and indirect forms of hostility and for social participation. It is apparent at this point that the close social environment is of great significance for practices enabling participation.

A particularly successful example of such occupations is the Antiga Massana in the Carrer de Floristes de la Rambla. This empty former music school, which is the new centre of the neighbourhood union, was occupied by the neighbourhood. Here, in the middle of the Raval, collective consultations take place, through which people who live in the Raval and are struggling can find support. Usually, those seeking support present their difficulties to the collective of a meeting, after which a solution is found together (fieldnotes from September 2021). Following this strategy, the activists can collectivise the individual housing problems and develop joint solutions.

For many people, the Raval—apart from its touristic attractiveness—is famous for being close to crime (e.g., “Droga, robos y okupaciones,” 2022; “El Mapa de los delitos,” 2017). And crime is indeed a problem in the district. There are 40 delicts per 100 inhabitants here. Among the major Spanish cities, Barcelona is also the one with the highest crime rate (epdata, 2024; “Los barrios,” 2020). The general crime rate and the high numbers in Barcelona and the Raval are directly linked to the touristification of the city. While over 200,000 tourists stroll daily along the Rambla, the people there live in unreasonable poverty (Solé Ollé et al., 2020; “My Barcelona is being destroyed,” 2024). However, the neighbourhood is tackling this problem itself. Because of the feeling that something had to be done against the crime there but also because of the criminalisation of people on the streets to enable more people to participate in public life, the residents developed new strategies. Some activists of the Sindicat d'Habitatge del Raval are working to enhance safety on the streets for the residents:

We have had a bit of a problem with insecurity, because...there is a small group of people who buy stolen things. We had serious problems with shoplifting, knife fights, things like that. So, instead of trying to deal with the issue, at first many reactionary neighbours called for the police. We tried to try to reoccupy public space. A market was organised among all the merchants, together with the neighbours, who every Saturday made a paella right there on the corner, which is the most problematic place [in the neighbourhood]. (Sindicat d'Habitatge del Raval/activist 02, interview 8 September 2021)

While some neighbours initially called in the police to deal with security in the district, other residents looked for alternative solutions. The activists distance themselves from the practices of securitisation through the police. This is also closely linked to the experiences of the district residents of being criminalised and stigmatised by the police (fieldnotes from September 2021). Searching for and finding their own ways to improve security in the district is also an important element in creating a basis of solidarity and further

deepening the close social environment. With the district festival mentioned above, which is held regularly every weekend, the neighbours reach a larger audience for small businesses as part of the *Sindicat d'Habitatge del Raval*, as well as a greater unity and presence of many people, within the framework of which the attacks by petty criminals have been curbed. Nearly every business established in the Riera Baixa street participates in the little festival, contributing at least with decorations or street food (fieldnotes September 2021). In this way, the residents collectivise the problem and give it a common answer.

In addition, the activists also organise care infrastructures in the Antiga Massana. These are particularly important since only under these conditions do people with low incomes doing shift work, and especially working in informal labour, have an opportunity to participate in social life:

Because Social Services require that women, in order to take care of their children, have to have either a job or decent housing, with a certain amount of square footage....So, it is always thinking about care and thinking about the specific contexts of...women: that you have to raise children, that they have no one to leave them with, that there is no family network. (Mujeres P'alante, interview 14 September 2021)

In the excerpt, the counsellor from the *Mujeres P'alante* initiative (women's counselling regardless of residence status) addresses the relevance of childcare services. Not only for the children does this mean the possibility of early participation in the education system, but the women are also dependent on it to be able to pursue wage labour. Participation in the labour market, in turn, is crucial for social participation as a whole (Brook, 2005; Naveed et al., 2024). Due to the very poor supply of care infrastructure in the neighbourhood, the activists of the Antiga Massana have come up with a joint approach and offer childcare in rotating procedures: "We made our own kindergarten!" (fieldnote from September 2021). Here again, the neighbours of the Raval established a collective answer to the individual problem of childcare.

The activists of the *Sindicat d'Habitatge del Raval* also organise free food distribution in the Antiga Massana, in which basic foodstuffs are redistributed to people that are donated by local markets and supermarkets, or which are collected by the activists. Sports activities to get young people off the streets—in the sense of low-threshold social work (e.g., Lawson, 2005)—also take place here, as do counselling services and a self-organised kindergarten (fieldnote September 2021).

The inhabitants of the Raval have established meeting spaces that facilitate interpersonal contact. The neighbourhood union offers counselling on matters about rent and other issues that fall outside the remit of the welfare state apparatus. In this way, the self-organised *Sindicat d'Habitatge del Raval* not only establishes an infrastructure that compensates for the deficiencies in the welfare state, but the activists also succeed in identifying diverse collective solutions to individual problems. The various practices of improving social participation in the close social environment contradict the tendencies towards individualisation.

## 6. Conclusion: Collective Responses to Individualised Problems

This article demonstrates how social participation can be made possible in hostile situations. It is apparent that the neighbours in the Raval district have become active themselves, thereby establishing at least a temporary infrastructure of participation through self-organised practices. In the context of hostility towards social participation, the individual issues encountered in the Raval neighbourhood are addressed through

collective responses. The hostility towards social participation as a situation is primarily the result of the individualisation of social problems. Housing, security, and care are three examples in which the residents of the Raval district contradict this individualisation and create something in common. On this basis, they can find collective answers to the individualised problems and improve social participation.

The neoliberalisation of social security systems, as outlined at the beginning of this article, primarily entails an individualisation of opportunities for participation. The transformations of the welfare state decollectivise the state's responsibility for enabling participation. The individual problems that arise as a result can be addressed at the level of the immediate social environment. The new relationships are established by the activists of the *Sindicat d'habitatge del Raval* and other groups and initiatives particularly in the meetings, and activated as a resource. Through the collective practices, the neighbours in the district themselves become activists and thus establish a local participation infrastructure that simultaneously becomes an infrastructure for welfare provision. This type of collective search for solutions is also linked to a sense of belonging to the district. This connection between participation and belonging crystallises in the neighbourhood union and points to a possible consolidation of the self-organised infrastructure. Furthermore, the transfer of the organisation of participation to civil society also occurs, which can be defined as a form of responsabilisation. The structures that emerge in this way achieve at least medium-term continuity and at least partially compensate for the deficient municipal infrastructure and connect to the historically extensive civil society organisations in Spain (Blanco et al., 2020).

As international studies show, civil society actors are becoming increasingly important in the context of the transformation of welfare state guarantees of participation (e.g., Castel, 2011; Heinze et al., 2021; Pera, 2020). My analysis also shows that local networks are becoming important. While some authors focus on networks for specific concerns (e.g., accompaniment when dealing with authorities; Bartolini, 2021, pp. 12–13), my analysis shows the importance of the immediate social environment, since social participation depends on how people live and can establish or participate in networks. This dependence means relying on individual circumstances and serendipity to get by, or in other words: The people who want to experience social participation despite a hostile situation must establish their own local networks to enable such participation. They must become active on their own and hope to be able to build appropriate relationships. This is possible in very different ways depending on the environment and good or bad luck.

Barcelona shows itself to be a model city in late capitalism and shifts the responsibility for the city's citizens to the citizens themselves (Delgado, 2017, p. 14). Transferring at least partial responsibility for social security to civil society tends to make the self-organised practices described above seem like a necessity to cushion the worst poverty. At the same time, collectively opposing exclusion and thus mitigating the individualisation of problem situations also becomes a task that takes on a life of its own. Marginalised individuals and groups must deal with difficulties here and, when state guarantee structures are no longer in place, are dependent on their social environment for social participation. All in all, this means that the opportunities to participate remain highly individualised and depend on voluntary structures.

In conclusion, I would like to emphasise that I have shown how self-organised practices in neighbourhoods activate residents and enable them to find answers to problems related to participation and livelihood. The article thus contributes to research on social participation by illustrating how social participation amidst hostility can be made possible. At the same time, the article shows how neighbours become

activists and reactivate or develop strategies for collectively dealing with problems. Those collective responses to individualised problems carry a transformative potential by developing alternative forms of social participation.

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The author declares no conflicts of interest.

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### About the Author



**Olaf Tietje** is a postdoctoral researcher at the Institute of Sociology at LMU Munich. He conducts research on labour, ethics and research ethics, gender studies, social transformations, migration/mobility, qualitative methods, sexuality, and social participation.

# Navigating Non-Invitation: Pro-Vaccine Choice Communities Amidst Exclusion and Public Participation

Barbara Morsello  and Paolo Giardullo 

Department of Philosophy, Sociology, Education and Applied Psychology, University of Padova, Italy

**Correspondence:** Barbara Morsello ([barbara.morsello@unipd.it](mailto:barbara.morsello@unipd.it))

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## Abstract

Between 2017 and 2021, specific health policy concerning vaccination in Italy contributed to the “non-invitation” of pro-vaccine choice communities to decision-making processes and public services with significant consequences for their societal life. This situation led to the emergence of new, often barely visible, participatory pathways. This article aims to examine the dynamics of exclusion and participation of pro-vaccine choice communities in Italy, adopting a science and technology studies (STS) framework that allows us to explore how non-invitation and participation are deeply entangled. Through digital ethnography and interviews, we investigate how individuals and communities navigate “non-invitation” and seek alternative avenues for participation. We observe their efforts to contest compulsory vaccination policies and legitimize their claims through political representation and independent scientific research. Despite facing stigmatization and marginalization, they employ various strategies to influence decision-making processes. However, challenges persist due to public stigmatization and punitive measures. Our findings highlight the nuanced interplay between dissenting perspectives, exclusionary practices, and participatory strategies in public health debates. The study underscores the ambivalence of participatory processes in knowledge societies, where participation and non-invitation often coexist, shaping the contours of public discourse and policy agendas.

## Keywords

non-invitation; participation; social movements; vaccine hesitancy

## 1. Introduction: Reframing Pro-Vaccine Choice Communities as Uninvited

This article investigates the efforts of individuals and communities in Italy advocating for vaccination choice, particularly in the context of the country’s stringent vaccination policies. Those individuals and communities,

here conceptualized as “pro-vaccine choice” embody a specific articulation of vaccine hesitancy. Vaccine hesitancy, as broadly understood, encompasses a wide spectrum of attitudes and behaviors towards vaccination, ranging from outright rejection to partial acceptance or expressing doubts about its safety and efficacy (Dubé et al., 2013; Larson et al., 2014; Sobo et al., 2016; Yaqub et al., 2014). This phenomenon involves not only individual behaviors but also collective concerns about the safety and efficacy of vaccination as a public health measure. A notable example of such collective resistance is “pro-vaccine choice communities,” which advocate for the autonomy to decide on vaccination while simultaneously demanding more rigorous standards of quality control (Blume, 2006).

These communities often experience non-invitation to decision-making processes concerning vaccination policies and, in some instances, marginalization from broader health policies and access to public services. Against this backdrop, this article pursues two interrelated aims. First, it examines how pro-vaccine choice communities and individuals navigated their exclusion from decision-making processes concerning vaccination policy in Italy between 2017 and 2021. Second, it highlights the key elements of this process, exploring how these “non-invitees” develop alternative modes of engagement across various public arenas, including scientific discourse and political deliberation.

Our analysis examines pro-vaccine choice communities in the context of the broader transformations occurring in the health and medical sectors further stressed by the pandemic crisis of 2020–2022. These changes include a growing reliance on evidence-based medicine, increasing challenges to medical authority by laypeople, and the introduction of laws that recognize patients as stakeholders in health policies. These transformations have led to the emergence of a rising number of health activist communities and groups in Western societies that focus on producing and mobilizing knowledge to influence the governance of health issues. This form of evidence-based activism (Rabeharisoa et al., 2014) is enacted by pro-vaccine choice groups, offering a lens through which to analyze their collective and individual activities as forms of participation in health policy, particularly regarding vaccination mandates. These communities, which oppose vaccination mandates, emphasize personal responsibility for their bodies and health, actively exercising their health citizenship by mobilizing personal biology to inform medical decisions (Jauho & Helén, 2022).

While the purpose of this article is not to evaluate the validity of pro-vaccine choice claims, it is crucial to consider these communities as examples of groups that refuse institutional knowledge (Neresini et al., 2024) and express disagreement with public policies related to the management of the body and health (Crabu et al., 2023). They advocate for the freedom to make vaccination choices and call for increased research and trials concerning vaccination matters. Indeed, although scholars often see vaccine hesitancy as a result of limited scientific literacy (Welch et al., 2023) or online misinformation (Kata, 2010; Lasco, 2020; Lavorgna & Di Ronco, 2019), science and technology studies (STS) scholars argue that vaccine rejection is not solely due to distrust in science or low literacy (Blume, 2006; Goldenberg, 2016, 2021; Larson et al., 2022). Instead, pro-vaccine choice communities embrace alternative epistemologies and expertise, challenging dominant scientific paradigms (Neresini et al., 2024). These communities frequently occupy marginal positions within scientific discourse and public health policy decision-making processes and, in certain contexts, experience exclusion from broader social life. Although there is a growing consensus in public health debates about the inclusion of marginalized groups (e.g., migrants, as discussed by De Freitas & Martin, 2015), this openness does not engage with vaccine hesitancy, health institutions primarily focus on promoting awareness campaigns assuming vaccine hesitancy stems from a lack of literacy. Indeed, vaccine hesitancy is considered

by the WHO as one of the 10 global health threats as of 2019, which underscores the necessity of finding solutions to convince people to get vaccinated. In this context, although research confirms the importance of adopting participatory practices and communications with vaccine-hesitant individuals (Tuckerman et al., 2022), two main types of public interventions are dominant in addressing vaccine hesitancy: first, by promoting scientific knowledge regarding vaccines, health institutions and practitioners set up informational and educational programs to influence the decision-making of laypeople; second, by implementing sanction regimes for individuals who choose not to get vaccinated. Often educational programs are based on the “deficit model”—which assumes that public misperception of science is due to a lack of knowledge—and sanction regimes, which indirectly contribute to framing vaccine-hesitant individuals and communities as lacking knowledge and information or as irresponsible and outlaw (Kaufman et al., 2018).

Considering the main institutional approach to vaccine hesitancy, the Italian case is paradigmatic. Pediatric vaccinations have been mandatory for accessing school since Law Decree No. 73 of June 7, 2017 (the so-called Lorenzin Decree), while during the Covid-19 pandemic, anti-Covid vaccination has been made mandatory for accessing workplaces and public spaces. The concerns of individuals from communities who advocated for vaccination freedom were not considered in the structuring of vaccination policies, resulting in their exclusion. Nevertheless, these groups of individuals and communities navigate non-invitation by creating spaces and pathways to amplify their participation in the vaccination discourse.

## 2. The Role of Media in the Public Construction of Non-Invitation

Newspapers are often regarded as trustworthy sources of information by the public, especially during times of crisis, playing a key role in shaping the agenda for matters of public concern. The media’s portrayal of public health issues both reflects existing public opinion and actively shapes it. Specifically, in the context of vaccination mandates, a connection has been identified between country-specific differences in newspaper coverage and people’s vaccination stances (Zimmermann et al., 2024). During specific circumstances—such as the Covid-19 pandemic and the increase of measles that set the Lorenzin Decree in motion—Italian newspapers always dedicate special attention to pro-vaccine choice communities and their claims. Following the introduction of mandatory pediatric vaccinations and the Lorenzin Decree, heated public protests from pro-vaccine choice communities erupted (Lello, 2020). At the time, the press used the label “no vax” (Giardullo, 2024) to refer to families opting against vaccination, perceived as a stigmatizing term by vaccine-hesitant individuals (Fattorini, 2023; Morsello, 2024). From this point, pro-vaccine choice communities gained prominent media attention in Italy leading to a significant polarisation of the public sphere, especially during the Covid-19 pandemic (Lello et al., 2022). Pro-vaccine choice received more media coverage when the government implemented more restrictive measures for those opting out of vaccination campaigns (Morsello & Giardullo, 2022). Notable instances include the 2017 mandate requiring pediatric vaccinations for school access and the pandemic years (2020–2021), during which anti-Covid-19 vaccines were mandatory for accessing workplaces and public spaces. Italian media also frequently covered the global controversy surrounding the AstraZeneca vaccine during this period (Sendra et al., 2023).

Between 2017 and 2020, Italian media acted as carriers of institutional messages, playing a significant role in suppressing dissent by favorably portraying those who conformed to established systems while disparaging dissenters who challenged sanction regimes (Morsello, 2022). As a result, individuals involved in dissenting politics were often depicted by the media as ridiculous, bizarre, and dangerous (Boykoff, 2006),

framed as “morally responsible” for vaccination during the immunization campaign. More broadly, the media often portrays pro-vaccine choice positions as anti-scientific and rooted in misinformation (Goldenberg, 2016, 2021), frequently dismissing the protests of the pro-vaccine choice movement as conspiracy theories (Bertuzzi, 2021). This portrayal often reconfigures and delegitimizes the meaning of their claims. Such framing has exacerbated social conflicts, as several studies highlight (Bharti & Sismondo, 2022; Hedges & Lasco, 2021; Lasco, 2020). The media identifies specific groups of “deviants” as representatives of “boundary crises” (Cohen, 1973) and, in the case of pro-vaccine choice individuals and communities, depicts them as irresponsible and selfish.

During the Covid-19 pandemic, vaccine hesitancy was frequently framed by experts as a public misunderstanding of science, casting it as a conflict between science and non-science. Terms such as “science denial” (McIntyre, 2018), “fake news,” “pseudoscience,” and “disinformation” became widely popular, reinforcing the metaphorical imagery of viral misinformation. Unverified news was seen by some as being as dangerous as the virus itself (Gobo et al., 2023). This framing reflected significant public concern over vaccine hesitancy as a problem of trust in science, raising important questions about the political and social consequences of declining trust in scientific authority. News coverage and discussions about vaccine mandates among policymakers further influenced how newspapers portrayed Covid-19 vaccination to the public (Zimmermann et al., 2024). This portrayal shaped perceptions, casting those who complied with vaccination mandates as “heroes” and those who resisted as “folk devils” (Morsello, 2023). During the pandemic, individuals advocating for the freedom of vaccine choice were subjected to public discrediting (Gobo et al., 2023; Lello et al., 2022). They were frequently portrayed as ignorant conspiracy theorists (Bertuzzi, 2021), gullible, and irresponsible, with their choices framed as a threat to public health (Goldenberg, 2021).

However, in doing so, the Italian press has also provided pro-vaccine choice communities an opportunity to gain visibility and increase their followers (Bory et al., 2023; Morsello et al., 2024). By including these communities in the public discourse on vaccinations, the press has indirectly facilitated the spread of their messages and their garnering of support. Although heavily oriented towards blame and discredit, it is reasonable to affirm that this “inclusion” gave an unprecedented resonance to non-invited voices. This visibility led to an increase in their followers within certain online spaces (Bory et al., 2023; Morsello et al., 2024) and greater political representativeness (Morsello & Giardullo, 2022). For this reason, it is crucial to understand how these communities and individuals have navigated non-invitation by promoting alternative models of participation.

### 3. Methods

This article is based on the research project concerning the so-called “refused knowledge community” (see Neresini et al., 2024). The qualitative study involved 18 months of research fieldwork (January 2020–July 2021) that included two main stages: (a) a digital multi-sited ethnography (Hine, 2020; Marcus, 1995) conducted across key associations and grassroots organizations of vaccination-hesitant individuals in Italy and (b) exploratory interviews with individuals who chose not to get vaccinated. In this article, we consider these data to deepen our understanding of how the exclusion of pro-vaccine choice communities is enacted in the daily lives of vaccine-hesitant individuals, particularly through the imposition of sanctions and how these are circumvented.

The interviews were conducted with the principles of constructivist grounded theory (Charmaz, 2009), with the aim of deeply exploring the complex phenomenon of vaccine hesitancy by prioritizing the perspectives of those who chose not to receive the Covid-19 vaccine and/or decided to avoid pediatric vaccinations. To this end, 21 qualitative interviews were conducted with individuals in Italy who exhibited vaccine hesitancy during the pandemic (2020–2021) and/or chose to avoid mandatory pediatric vaccinations introduced in 2017. The majority of participants were women (14), as women play a central role in family health decisions, including vaccination choices (ECDC, 2016). Seven men were also included to capture a broader range of perspectives, particularly those of parents managing pediatric vaccination requirements and decisions regarding Covid-19 vaccination. Participants, aged 30 to 70, were recruited using snowball sampling, which required building trustful relationships with vaccine-hesitant individuals: a especially challenging task during the Covid-19 pandemic (Morsello, 2023). Interviewees were asked to provide contacts of others who might be willing to participate.

The interviews focused on three main areas:

1. Reconstructing the biographical pathways that led participants to choose not to vaccinate their children or themselves;
2. Exploring how vaccine-hesitant individuals construct alternative forms of knowledge and practices related to health and wellbeing;
3. Examining how sanctions impact their daily lives and decisions.

Throughout the interviews, significant emphasis was placed on understanding participants' perspectives empathetically, given the sensitive nature of the topic under investigation.

While the first phase of the research aimed to analyze vaccine hesitancy as a private choice, the second phase focused on exploring its public dimensions. Specifically, the study involved pro-vaccine choice communities in Italy to understand how these groups build heterogeneous forms of participation, despite being excluded from official institutional discussions on vaccination policies. This phase utilized connective (Hine, 2020) and multi-sited (Marcus, 1995) digital ethnography across various online platforms, including Facebook, YouTube, webinars, and instant messaging services, engaging with prominent Italian pro-vaccine choice associations (see Table 1). The methodological approach consisted of two steps: first, a screening process to map the online ecology of groups and associations, and second, a targeted digital ethnography examining a subset of groups through their online spaces (e.g., websites and social media accounts). This involved collecting shared content, such as posts, images, comments, and links.

The screening process identified 41 active associations in Italy advocating for vaccine choice, spanning both local and national contexts. Selection criteria for inclusion in the screening included: (1) maintaining websites and/or blogs and (2) demonstrating continuous activity over time (minimum one post per week). The screening revealed a complex and interconnected network, comprising national associations closely linked to local committees and supported by doctors and lawyers advocating for free choice of vaccinations. Following the mapping of the Italian pro-vaccine choice movement landscape, three groups were selected for in-depth digital ethnographic fieldwork: Comilva, Corvelva, and Movimento 3V (M3V; see Table 1). These groups were chosen for their leading roles in disseminating information, offering counter-information, and organizing webinars, online meetings, and social gatherings during the Covid-19 pandemic, both nationally



**Table 1.** Main Italian pro-vaccine choice associations involved in the ethnography.

Association name	Description	Online spaces observed
Comilva	Comilva is the acronym for Coordinamento del Movimento Italiano per la Libertà Vaccinale (Coordination of the Italian Movement for Freedom of Vaccination). Operating since 1993, it is one of the oldest groups in Italy focusing on freedom of vaccination and is responsible for giving legal support to those harmed by vaccines, disseminating information on the risks of vaccination, and applying institutional pressure against compulsory vaccination. It also uses a pool of experts through which they conduct studies on vaccine efficacy.	<a href="http://www.comilva.org">www.comilva.org</a> <a href="https://www.youtube.com/user/comilvatrieste">https://www.youtube.com/user/comilvatrieste</a> <a href="https://www.facebook.com/ufficiostampacomilva">https://www.facebook.com/ufficiostampacomilva</a>
Corvelva	Coordinamento Regionale Veneto per la Libertà delle Vaccinazioni (Veneto Regional Coordination for the Freedom of Vaccinations) was founded in 1993 and holds as its main principle the freedom to be vaccinated. Corvelva supports members who wish to undertake a path of free-choice vaccination. Corvelva disseminates information on the risks of vaccinations, both online and with ad hoc events. Corvelva supported a pool of experts working to assess the safety of mandatory vaccines (tetraivalent).	<a href="https://www.corvelva.it">https://www.corvelva.it</a> <a href="https://www.facebook.com/corvelva">https://www.facebook.com/corvelva</a> <a href="https://www.youtube.com/channel/UCju4FYwvtWwQlQtD9sIG3-g">https://www.youtube.com/channel/UCju4FYwvtWwQlQtD9sIG3-g</a>
M3V	Born as a political party in 2019, M3V lists as a goal supporting constitutional rights (“let’s save the Constitution”) and free therapeutic choice. M3V strives above all to give a voice and represent its members by actively participating in regional and local political life. They also promote free information through ad hoc YouTube channels.	<a href="https://www.movimento3v.it">https://www.movimento3v.it</a> <a href="https://www.facebook.com/Movimento3V">https://www.facebook.com/Movimento3V</a>

and locally. They also exemplify different styles of activism addressing the vaccination controversy. Moreover, Comilva, Corvelva, and M3V are among the oldest pro-vaccine choice groups in Italy and represent the heterogeneity of the Italian pro-vaccine choice movement.

In the selected social media spaces (see Table 1), we followed publicly available conversations, reposted content, and public invitation links to social media-based groups. This approach resulted in a sample of more than 30 online spaces, including open personal Facebook profiles, Facebook pages, Facebook groups, YouTube channels, blogs/websites, video lessons, and Zoom webinars. To collect ethnographic field notes, we used a shared template to draft weekly diaries. This method facilitated constant comparisons, such as examining health-related practices or discourses on public health measures (see Crabu et al., 2023).

After collecting data from interviews and digital ethnography, we coded the empirical material following the principles of constructivist grounded theory (Charmaz, 2009), enabling an iterative and reflexive process of data analysis. In presenting our findings, we followed the approach suggested by scholars like Jackson (1990),

Rapp (2011), and, more recently, Lewis et al. (2014). Rather than viewing empirical data as isolated pieces of information, this approach considers them as triggers to describe and analyze online settings.

#### 4. Experiencing Exclusionary Practices in Everyday Life of Vaccine-Hesitants

Vaccine hesitancy has of late emerged as a major public health issue, prompting specific policy responses. During the Covid-19 pandemic, Italy further expanded sanctions on the unvaccinated, including workplace suspension without pay for certain professionals, such as healthcare workers and teachers, tightening the 2017 decree that mandated up to 10 childhood vaccinations for school attendance. These exclusionary policies have had tangible consequences, with many interviewees reporting experiences of social exclusion and marginalization due to their vaccine hesitancy. This often compels individuals to conceal their beliefs to avoid being labeled as proponents of conspiracy theories or purveyors of fake news. During the Covid-19 pandemic, this sense of social exclusion intensified for those who distrust traditional epistemic authority (Grodzicka & Harambam, 2021) often resulting in distancing from their own circles of friends, family, and colleagues. For instance, L., a vaccine-hesitant individual, describes the profound loss of social ties stemming from his views on the Covid-19 pandemic:

Fuck, it hurts! I can't share my ideas because nobody listens to me or because they consider me an asshole, no matter what I say....This hurts me! And if I want to talk with someone, there is no one I can talk to, and this upsets me. The communication with friends who I have known for 15 years is breaking down. For the first time I felt different and uncomfortable from them during lockdown because I didn't [get] vaccinate[d]...we have been friends all my life, but vaccination choice made everything different....It's crazy and it's mentally devastating for me! It seems that if you choose not get vaccinated, you have no morals or ethics....I'm upset about [it], not because of the restriction to enter in bar[s] or public places, but because I can't talk to my friends anymore. (L., male, 7/9/2021)

Conflicts with family and friends left L. navigating a sense of alienation within his social circles. This highlights the emotional toll of vaccine hesitancy and its profound impact on interpersonal relationships in an increasingly polarized society.

The public representation of pro-vaccine choice (see Section 2) played a leading role in labeling hesitant individuals as “immoral” or “irresponsible,” a perception reinforced by sanction regimes. During the Covid-19 pandemic, for example, unvaccinated people were barred from entering public places such as bars, shops, cinemas, supermarkets, and other venues where social interactions occur, due to anti-Covid norms. The social pressure to get vaccinated was very high also in other European countries, and included pressure from peers, colleagues, friends, relatives, as well as from health authorities such as one's doctor, by whom one would feel judged or blamed for choosing not to vaccinate (Paul et al., 2022). In our study, participants often report experiences of exclusion dating back to periods before the pandemic. For instance, in response to the 2017 Lorenzin Decree, one pro-vaccine choice mother shared her own experience regarding the violation of pediatric vaccination requirements:

Teachers allowed us to enroll our children in school without vaccinations, even though they knew it was illegal. It was common knowledge that this wasn't permitted, which is why some of us hadn't enrolled our children. But then we started receiving calls from the teachers, saying: “Please enroll your

children, or many teachers will lose their jobs this year.”...Here in our small village, everyone knows each other, and the teachers began warning us: “There are two fewer children this year, a class will be canceled, and Teacher R. will be left without a job.” So they allowed us to enroll our children, formed the classes, and our children attended school—for only three days. Now, I feel like crying because it was such a painful experience for us. I still carry it with me, in my mind. Then the police came to our house [pause, the interviewee starts crying]...bringing us a warning and telling us: “If you take your children to school, we will report you for child neglect because unvaccinated children cannot attend.” (T., female, 15/1/21)

The experiences of exclusion reported by research participants can intensify feelings of abandonment by public institutions that are supposed to protect them. This exacerbates discontent and can lead to conflictual public actions aimed at asserting personal experiences of suffering, deprivation, and perceived abandonment by the state. Moreover, it is noteworthy in the interview that while sanctions enforce exclusionary practices, there are actors often involved in guarding the accessibility of public spaces who encourage participation, even when it is officially prohibited, for purposes that extend beyond institutional aims. This is evidenced in reported cases where teachers open the possibility of enrolling unvaccinated children in school despite prohibitions, to solve emergent problems of unemployment raised by the sanction regimes. This process reveals how “pockets of participation” (Francks, 2011; Ricks, 2015) can coexist with sanction regimes where official participation is not permitted. These communities and individuals occupy alternative spaces to access services from which they have been excluded, circumventing sanction regimes and building participatory pathways. This is evident in the strategies employed by vaccine-hesitant individuals to circumvent sanctions related to compulsory pediatric vaccinations. For example, some hesitants chose not to send their children to kindergarten, opting instead for homeschooling:

Yes, my daughter only attended kindergarten for two years and then stopped. She struggled a bit at first, but we eventually found other solutions like homeschooling, and it worked out well. (V., female, 23/2/21)

Another strategy has been postponing vaccination appointments. In Italy, local health agencies send parents a letter with the date of the vaccination appointment. This letter lists the vaccinations offered, including those mandatory under Law 119/2017. Parents are allowed to postpone the appointment once, but from the second time onward, they must provide appropriate documentation explaining the reason for the delay. Vaccine-hesitant parents report postponing vaccination appointments for as long as possible, often until they receive a warning letter. Simultaneously, the local school or educational service is notified by the health institution about the child’s non-compliance with vaccination requirements. For children aged 0–6, this can result in exclusion from educational services. Ultimately, families receive a penalty. The exclusion from traditional educational services encourages some families who choose not to vaccinate their children to explore alternative educational options, such as nature-based education or programs like kindergartens in the woods and outdoor education:

I get constant reminders, like letters inviting me to meet with health personnel about vaccinations, or letters saying: “Why don’t you [get] vaccinate[d]? You’re putting your child at risk!” And blah, blah, blah....I had to pay the fine for both of my children. At first, I delayed the vaccination appointment, saying: “Look, I’ll [get] vaccinate[d], but later.” They made a fuss about it, and then they started

sending reminders instead. So, I couldn't send them to school and found an alternative solution, like kindergartens in the woods. (M., male, 1/15/2021)

Kindergartens in the woods are often associations established to promote outdoor education, primarily in natural settings like forests, fostering close contact with nature. In recent years, these programs have gained popularity among parents who are vaccine-hesitant but cannot keep their children at home. In addition to not requiring mandatory vaccinations, kindergartens in the woods promote alternative educational models focused on a more natural approach to children's well-being. These strategies, used to navigate vaccination requirements, reconfigure pathways of participation, bringing together families of vaccine-hesitant individuals. In these spaces, families share values and perspectives on health and well-being, while exploring alternative conceptions of care:

Families who have learned about the project [a kindergarten in the woods] have joined and formed a community with other parents, truly creating a participatory network....Some families are very conscious about nutrition, the natural materials used in their children's clothing, and the types of toys they allow, carefully choosing what is best and avoiding others. They often avoid watching television as well. Some parents were already practicing this lifestyle before joining the project, while others adopted these values after connecting with the community. Through this exchange of ideas and experiences, families learn from each other. Additionally, we organize monthly training sessions for parents to further support this shared vision. (A., female, 10/11/2020)

## 5. Pro-Vaccine Choice Communities Building Participation and Engaging in Policymaking

M3V is a prominent example of a rounded and systematic attempt to circumvent non-invitation. M3V was established as a political party in 2019 to support freedom in therapeutic choice as fundamental citizens' rights (see Table 1). In 2020–2021, it primarily opposed Covid-19 vaccination by arguing the unconstitutionality of mandatory vaccination. Later it achieved electoral success at various levels of government—local, municipal, provincial, and national. M3V strives to represent its members by actively participating in regional and local political life, while also disseminating information through dedicated YouTube channels. The political engagement of M3V aims to challenge the methods through which health policies are formulated, questioning the reliance on scientific knowledge while highlighting the prioritization of these policies over ethical considerations and individual self-determination (Morsello & Giardullo, 2022). With over 46,000 followers on Facebook, M3V stands as a pioneer among Italian political parties emerging from movements advocating for freedom of choice in vaccination. Beyond the vaccination issue, central to M3V's political ethos is the prioritization of human welfare and health as it is presented in their vision:

The M3V political party operates with the sole intent of pursuing the common good, that is, the welfare of all citizens, in harmony with the environment and all forms of life. The human being is not a number within standard procedures, but a being endowed with consciousness, unique and unrepeatable, and as such must be considered so that dignity and freedom can be restored to him. The freedom of the human being today is gone on the basis of hypothetical medical-scientific justifications that, according to doctors and scientists, are nonexistent, false, or wrong to the core. (M3V, n.d., translation by the authors)

The M3V seeks to build bottom-up participation by prioritizing individual rights in its political agenda. It opposes vaccination policies designed to protect societal health through interventions on individuals, advocating instead for a “society on a human scale” where everyone is seen as “unique and irreplaceable.” Consequently, M3V argues that no medical intervention should be accepted as mandatory, as such mandates violate the integrity of human individuality.

M3V aims at reconsidering the role of citizens first, and foremost, as free human beings. By reframing vaccination as a violation of individual freedom, M3V aims to elevate pro-vaccine choice claims into the political arena, seeking to influence decision-making processes regarding vaccination-related issues. Specifically, during the Covid-19 pandemic, M3V rhetorically transformed the virus into more than just a health issue; it became a political symbol representing a new societal vision that favors anti-social political measures aimed at suppressing individual freedoms, as demonstrated in the following quotation:

We are going through a historical moment in which civil rights are becoming less and less...in the name of a health emergency. Workers have been deprived of the possibility to access work, sowing uncertainty, instability and undermining their dignity as human beings, but every form of freedom of the individual, in the name of a presumed protection of the common good, is being eroded. We have immediately recognised the authoritarian drift to which this government proves to want to take us, using the health emergency from SARS-COV-2 as a ruse to justify this situation and that has made its way initially with the laws on compulsory vaccination for children, accompanied by coercive aspects for citizens...We carry on the fight against this slavery and fear of living, together, united, for the restoration of legality and our constitution. (M3V, 2020, translation by the authors)

M3V contests compulsory vaccination campaign by framing the Covid-19 pandemic as an “authoritarian drift” by the government to undermine individual rights and freedoms. It should be noted that anti-Covid vaccination was not compulsory while specific job categories—such as healthcare personnel and school and university staff—were required to get vaccinated to access the workplace; strong recommendation was applied to individuals aged 12 or older. This mandate was enforced through the exclusion of unvaccinated individuals from essential spaces and rights. From the M3V perspective, this meant that the obligation for anti-Covid-19 vaccination was extended to almost the entire population because the unvaccinated were socially excluded from many public spaces. Notably, during the Covid-19 pandemic in 2020, M3V garnered nearly 11,000 votes in the northern region of Emilia Romagna by contesting the anti-Covid restrictions and sanctions. In 2021, it achieved another milestone by electing its first representatives in the municipalities of Rimini and Trieste. Today, M3V provides various training services aimed at fostering public participation in vaccine-related issues and the interaction between government and public health. These services take the form of “policy workshops” designed as laboratories or schools where participants actively engage in shaping new policies together. The objectives of M3V’s *officina politica* (political workshop) are twofold: (a) to train activists on M3V’s political stance to build a cohesive front of knowledge and values, and (b) to disseminate, explain, and discuss the key issues outlined in M3V’s electoral program. This suggests that pro-vaccine choice communities are not merely protest movements but have made concerted efforts to build grassroots participation and political pathways to influence vaccination policy and beyond. The strategies employed by groups like M3V to establish these participation channels reveal a clash between the perspectives of excluded individuals and government policymakers. This clash reflects not only divergent views on vaccination but also broader tensions regarding health management and citizenship.

Conversely to M3V's assertion that the freedom of vaccination choice stems from the belief that individuals have the right to decide about their own bodies and health, other communities argue that vaccination should be voluntary due to potential health risks. Consequently, these communities strive to participate in the scientific arena by supporting independent research projects aimed at investigating the alleged health risks associated with vaccines. In doing so, they attempt to counteract the prevailing media narrative that portrays pro-vaccine choice communities as fanatical or ignorant by appealing to science to legitimize their claims.

This approach is exemplified by Comilva and Corvelva, two of the oldest pro-vaccine choice associations in Italy. These associations are engaged in various participatory practices, including fundraising, citizen science campaigns, and building alliances with institutional actors. For instance, after the 2017 Lorenzin Decree, which mandated pediatric vaccinations for school attendance, Corvelva initiated an independent research project in 2018 to assess the biological composition and safety of the MPRV vaccines. This project successfully raised over 50,000 euros through a fundraising campaign supported by the active participation of the association's members and supporters as the Italian Order of Biologists (Guglielmi, 2018). The results of the study were published on March 31, 2020, in the journal *F1000Research*, and were announced on the Corvelva website as the "first peer-reviewed publication on MPRV vaccines Priorix Tetra":

These results conclusively confirm the presence of fetal DNA in Priorix tetra vaccines, in variable quantities between the various batches, indicating poor quality control of these pharmaceutical products. (Corvelva, 2024, translation by the authors)

Indeed, the study highlights concerns about the purported lack of quality control in vaccinations, accusing official institutions of inadequately performing these checks. As a result, it argues that vaccinations should not be made compulsory for individuals.

Another example of how pro-vaccine choice communities circumvent non-invitation to the scientific arena and build alternative participatory practices can be seen in the project Studio Anticorpali funded by Comilva. This project consists of an observational study that relies on the voluntary participation of individuals from both vaccinated and non-vaccinated populations. The study aims to provide a descriptive overview of the immune status of these individuals concerning specific infectious diseases by measuring their antibody titers.

Participants in the study undergo blood draws at contracted laboratories to measure Th1 and Th2 values, which serve as indicators of immune responses to various infectious diseases. The active involvement of laypeople in constructing evidence was particularly encouraged during 2019, with numerous events organized across Italy to inspire people to participate in the project. The project is also presented through the association's webpage and a dedicated website, where the rationale for the study is explained:

In Italy, there is a lack of data regarding antibody responses to vaccine protocols for infectious diseases, as well as immune responses following natural diseases or infections. This data gap exists not only for the general population but particularly for the pediatric population. There are no controls on vaccine efficacy, and the available literature data are not conclusive. (Studio Anticorpali, n.d., translation by the authors)

In this way, the project aims to address presumed gaps in official scientific understanding, particularly concerning the immune response of the general population to vaccination, resembling early attempts at popular epidemiology or bottom-up examples of “citizen science” (Giardullo, 2023). However, in opposition to the scientific establishment, they collect data and set up research questions and problems (Bonney et al., 2009; Haklay, 2013; Hecker et al., 2019). By building participatory practices that include laypeople, experts, and institutional alliances, they not only challenge the scientific credibility of public health policymaking but also aim to address alleged gaps in scientific literature, contributing to policy-making even without formal invitation.

## 6. Conclusion

The enactment of coercive public policies, including the Lorenzin Decree of 2017 and measures implemented during the Covid-19 pandemic, catalyzed the emergence of pro-vaccine choice communities and vaccine-hesitant individuals as distinct categories of “non-invitees” to both public policymaking processes and broader social life. These circumstances, perceived by these groups as authoritarian, led them to navigate non-invitation that often resulted in social exclusion and stigmatization making the participation of pro-vaccine choice individuals and communities difficult as reported in the cases presented. These groups were often labeled as ignorant and lacking knowledge or deemed irresponsible and deserving of punishment for their choice not to get vaccinated, a decision perceived as dangerous both to themselves and to society at large. Sanction regimes aimed at encouraging vaccination effectively excluded individuals from public life, leading many individuals to feel marginalized within public spaces and their social networks. The label of irresponsibility had tangible effects on public perception, even influencing how these individuals were viewed by their family and friends. However, non-invitation contributed to giving them the possibility of building alternative pathways of participation and meeting other people who share the same views and values, for example regarding health and wellbeing, as in the case of outdoor education.

Additionally, sanctions implemented to counter the vaccine hesitancy phenomenon through coercive measures, despite impacting social ties and access to certain public spaces, revealed the “covert actions” of some actors who opened spaces for the participation of vaccine-hesitant individuals. These actors, who are responsible for guarding the boundaries of accessibility in certain everyday contexts, sometimes favored the inclusion of vaccine-hesitant individuals to pursue personal objectives, rather than excluding them, to solve problems that arise as a consequence of sanctions such as the unemployment of teachers due to many unvaccinated children dropping out of school. These processes highlight how pockets of participation can emerge even in perceived authoritarian situations, where coercive measures are implemented to limit the involvement of certain social groups. This is evident among vaccine-hesitant families who, in their attempt to avoid mandatory vaccinations, create pathways of participation with other families, adopting alternative educational and care models. By doing so, they effectively circumvent sanction regimes by occupying alternative spaces to access services and opportunities from which they have been excluded.

Through our analysis, we also observed how pro-vaccine choice communities in Italy, such as Comilva, Corvelva, and M3V, navigated exclusionary practices. These communities adopted diverse approaches: M3V contested compulsory vaccination policies by framing them as violations of individual rights and constitutional freedoms, engaging in political representation, and advocating for greater individual autonomy in health-related decisions. Meanwhile, Comilva and Corvelva sought to legitimize their claims by conducting



independent scientific research on vaccine safety and efficacy. By leveraging citizen science initiatives such as the Studio Anticorpali, these communities aimed to address perceived gaps in official scientific understanding and inform public health institutions.

This analysis reveals not only how these communities challenge the scientific and political authority of public institutions but also highlights a clash of worldviews concerning the management of health and wellbeing in society. It showcases alternative conceptions of science and citizenship where the public plays an active role in the knowledge production processes. The effort to have their voice heard within the political and scientific arenas reflects a broader trend towards bottom-up citizen engagement and the democratization of knowledge production (Delvenne & Macq, 2020; Siffels et al., 2021).

Examining the construction of non-invitation for pro-vaccine choice communities by coercive policies, and how individuals and communities have circumvented such exclusions, reveals a complex interplay of competing knowledge claims, exclusionary practices, and participatory strategies. Groups such as M3V, Comilva, and Corvelva have emerged as significant actors in the discourse surrounding vaccination policies and practices, despite their exclusion by health institutions and frequent stigmatization by the media.

Pro-vaccine choice communities face substantial challenges in their efforts to gain recognition and influence decision-making processes regarding vaccination policy. The implementation of punitive measures and sanctions exacerbates social tensions, further deepening the divide between pro-vaccine and anti-vaccine factions. Despite these difficulties, pro-vaccine choice communities persist in advocating for their beliefs, aiming to reshape public narratives and policy agendas.

Rather than achieving the intended marginalization of these groups, coercive measures often result in forms of social exclusion that do not effectively diminish their claims. Furthermore, this reveals that counter-participation practices are not solely aimed at challenging mainstream institutions and policies but also demonstrate how marginalized groups, even in authoritarian contexts, embody and assert different values and worldviews through their claims. These groups find ways to spread their messages and sustain their participation, even in adverse conditions. This helps us understand that inclusion and exclusion, as well as participation and non-invitation, are often intricately intertwined processes.

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### Conflict of Interests

The authors declare no conflict of interests.

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### About the Authors



**Barbara Morsello** is an assistant professor of sociology at the University of Padova and a member of the Padua Science, Technology, and Innovation Studies (PaSTIS) Research Unit. Her research interests revolve around the relationship between biomedical innovation, everyday life, and clinical practices, with a particular emphasis on knowledge co-production. Recently, she has explored the production of refused knowledge in pro-vaccine choice communities during Covid-19 and contributed to a FET-Horizon 2020 project on the clinical and social implications of intelligent neuroprostheses.



**Paolo Giardullo** (PhD) is a tenure assistant professor (RTT) of sociology of the environment at the University of Padova. He contributed to research projects on topics such as responsible research and innovation, citizen science and public engagement, air quality policies, and refused forms of knowledge. In parallel to these experiences, he is aiming to investigate environmental and innovation issues by combining web data, media analysis, and fieldwork informed by an STS framework.

# From Criminal to Crucial Participation: The Case of Dutch Volunteer Hackers

Anne Marte Gardenier 

Department of Industrial Engineering and Innovation Sciences, Eindhoven University of Technology, The Netherlands

**Correspondence:** Anne Marte Gardenier ([a.m.gardenier@tue.nl](mailto:a.m.gardenier@tue.nl))

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## Abstract

Since the 1980s, Dutch volunteer hackers have been identifying and disclosing vulnerabilities in computer systems. Initially criminalized, these hackers now play a crucial role in Dutch cybersecurity governance. This article explores the transformation of hackers from criminals to crucial participants and examines what this case reveals about citizen participation in the digital age. The case study demonstrates that citizens can play a pivotal role in addressing challenges posed by digitization, although their contributions can remain unrecognized and constrained by hostile institutions. This article aims to deepen the understanding of various forms of citizen participation in digital society, how institutions can support or constrain them, and how citizens play a central role in shaping these institutions to legitimize their participation.

## Keywords

cybersecurity; digitization; material participation; technological citizenship; uninvited participation; volunteer hackers

## 1. Introduction

Digital technology permeates almost all aspects of contemporary life and is bringing a plenitude of opportunities, but also just as many risks. For instance, the information and communications technologies (ICT) that underlie today’s digitized society contain vulnerabilities. These vulnerabilities include small technical errors in systems that can be exploited to make the system work differently than intended. Such vulnerabilities make it possible to carry out cyberattacks, such as ransomware, theft, stalking, and spying. Unattended vulnerabilities have the potential to disrupt the lives of individuals and essential societal processes. For example, human rights defenders, lawyers, and journalists around the world have fallen victim



to spyware like Pegasus (Benjakob, 2022), and hospitals, pharmacies, and universities have faced ransomware attacks, disrupting the continuation of their services. Vulnerabilities must be discovered as quickly as possible so that they can be patched and no longer be exploited, which is a key tenet of cybersecurity research.

An important principle of cybersecurity research is to enhance the cyber hygiene of ICT users. Ordinary ICT users are widely recognized as the “weakest link” in cybersecurity (Yan et al., 2018), indicating an alleged lack of knowledge and skills to avert cyberattacks. For that reason, cybersecurity research and governmental policy strategies often focus on improving user awareness of cybersecurity practices, viewing user behavior as one of the biggest challenges to maintaining cybersecurity (European Union Agency for Cybersecurity, 2022; Kävrestad et al., 2024). Such approaches pinpoint the “deficient user” as the security risk (Klimburg-Witjes & Wentland, 2021).

While the lack of knowledge and skills of ordinary users to avert cyberattacks is certainly an important problem, portraying the ordinary user or citizen, in general, as the deficient user does not fully do justice to their role in cybersecurity. In fact, this article demonstrates that citizens can play a central role in cybersecurity governance. In the case of Dutch volunteer hackers, which will be described in this article, citizens have independently and voluntarily contributed to establishing a cybersecurity governance system in which they now play a crucial and central role. Since the 1980s, these hackers have aimed to make the internet safer by exposing vulnerabilities. Initially, the Dutch government viewed hacking as illegal and criminalized it. However, over time, the perspectives of the government and other cybersecurity stakeholders shifted, and today the contributions of volunteer hackers to cybersecurity governance are recognized and encouraged, albeit with certain limits. Common terms used to describe well-meaning hackers who aim to improve cybersecurity through hacking or other means are “white hat” or “ethical” hackers. These terms have been associated with hackers affiliated with corporations (Goerzen & Coleman, 2022). In this article, “volunteer hackers” is used to describe and analyze the case study, as it focuses on hackers who voluntarily and independently contribute to improving cybersecurity governance.

The disclosure of vulnerabilities by these hackers and others around the world has been crucial for the development and security of the internet (Goerzen & Coleman, 2022). This demonstrates that viewing citizens as the “weakest link” overlooks their potential role in cybersecurity governance. Citizens can significantly contribute to the governance of cybersecurity, and digitization in general, but their potential for participation can remain unrecognized and unsupported by institutions. This indicates an institutional mismatch (Marres, 2012) regarding citizen participation in the digital domain. An institutional mismatch arises when existing structures fail to recognize or support emerging forms of citizen participation, such as ethical hacking. While cybersecurity campaigns assume a lack of citizen engagement and aim to foster participation where it is allegedly absent, in reality, citizen participation does occur but is not always acknowledged by institutions.

This case study shows that citizens can play a central role in addressing digitization challenges, such as raising awareness about insecure computer systems. However, there is limited research on how institutions support or constrain citizen participation in digitization, partly due to a narrow view of what constitutes “participation” in the digital society. This article aims to enhance understanding of various forms of citizen participation with regards to digital technologies, how institutions can support or constrain the participation of citizens on the



one hand, and how citizens can play a central role in shaping these institutions on the other (cf. Giddens, 1984). By applying the framework of technological citizenship (Gardenier et al., 2024) to a case study analysis of Dutch volunteer hackers (Gardenier, 2024), this article explores hacking to disclose vulnerabilities as a form of citizen participation. It clarifies how institutions can support or constrain this type of participation, and highlights how hackers have “legitimized their craft” (Goerzen & Coleman, 2022, p. 7) and shifted from being seen as threats to security to being recognized as valuable contributors to it.

This article is structured as follows. Section 2 reviews literature that explores emerging forms of participation in the digital society, connects these ideas to the framework of technological citizenship, and discusses the role of institutions in supporting or constraining these new forms of citizen participation. Section 3 describes the case study, demonstrating the transition of volunteer hackers from perceived criminals to crucial participants in Dutch cybersecurity governance over three distinct periods. In Section 4, the framework of technological citizenship is applied to the case study, and further discussion is provided on what this case reveals about citizen participation in the digital society. The article concludes with recommendations for further supporting volunteer hackers and a summary of the key findings.

## 2. The Diversity of Citizen Participation in the Digital Society

Literature on the relationship between participation and digitization has often focused on how digital devices facilitate particular types of political engagement and citizen participation. For instance, scholars have investigated how social media might affect citizens’ participation in civic and political life (Boulianne, 2015), the role of digital technology in enabling and enhancing democratic practices and forms of governance (Fischli & Muldoon, 2024), and the use of digital tools to promote so-called e-participation (Hovik & Giannoumis, 2022).

While these approaches offer valuable insights into the impact of digitization on political participation and engagement, they demonstrate a narrow understanding of “participation” in the digital society. Chilvers and Kearnes (2015) have shown that dominant theories about participation have mainly focused on criticizing and improving top-down organized participation methods. This perspective views “the public” as an already existing, well-defined group that should be invited to participate to make their concerns about clear and specific issues heard.

In contrast, Chilvers and Kearnes (2015) argue that public participation should be seen as emergent and “in the making” (p. 4). They understand publics as being actively formed in the process of citizens articulating and addressing their shared matters of concern. For Chilvers and Kearnes, the goals of participation, the groups of people involved, and what is considered “political” are never given but always co-emerge. Therefore, for Chilvers and Kearnes, what is understood as “participation” should also encompass citizen practices beyond formal, top-down, organized public deliberation, such as “uninvited, informal, citizen-led, material, digital, mundane, private, [and] everyday” (Chilvers & Kearnes, 2020, p. 355) activities.

This links to Dewey’s (2016) and, more recently, Marres’ (2007, 2023) pragmatist view of “the public” as forming around collectively articulated and addressed issues. In this view, when citizens encounter a problem—which may be catalyzed by the rise of new technological applications in society—that requires government action, they emerge as a public by collectively framing and attempting to address the issue.

What publics become concerned with is not predetermined but emerges through this collective process of defining and responding to the issue. As citizens engage in this process, they gradually form a public. In this view, public participation naturally arises from the bottom up based on citizens' shared efforts to articulate and address concerns. Therefore, participation does not occur in predefined places, by predefined groups, or over predefined issues. Instead, publics emerge through the ongoing process of collectively identifying and attempting to address the issues they define as important.

Moreover, citizen participation is not limited to traditional forms of political engagement such as voting or protesting. Researchers in science and technology studies have expanded the understanding of participation in relation to technology. For instance, Marres (2012) has demonstrated that citizens' material interactions with technology in the private sphere may also constitute participation. Traditional political philosophers like Aristotle and Hannah Arendt emphasize that public activity is a key aspect of participation (Arendt, 1958), while material involvement is linked to private, domestic life (Marres, 2012). However, Marres argues that interactions with technology in private settings can also sometimes be understood as participation. She demonstrates this with the example of publicity campaigns that promote actions such as heating, cooking, and washing at home as ways to engage with issues like climate change and resource depletion. This was particularly evident in the Netherlands in 2022 when the government launched a campaign urging citizens to lower their heating to 19 degrees due to the gas shortage caused by the sanctions imposed on Russia after the invasion of Ukraine. These campaigns demonstrate how citizens' everyday interactions with material objects can facilitate public action on environmental issues.

This material perspective on participation broadens the concept to include engagement with technology in private settings. It can be effectively used to explore practices like hacking to disclose vulnerabilities as a form of participation where citizens address their shared concerns through a material practice that may be performed from their homes.

### ***2.1. Technological Citizenship: A Framework for Understanding Citizen Participation in the Digital Society***

The framework of technological citizenship (Gardenier et al., 2024) captures this perspective on citizen participation as emergent and taking place in multiple life spheres as described above, all within a single framework, and specifically related to digital technology. This framework can be used to scrutinize and assess the roles of citizens in shaping the digital society. It recognizes a broad range of citizen actions as forms of participation. Based on liberal, communitarian, and republican perspectives on citizenship, it conceptualizes citizen participation in relation to digital technologies in three distinct but overlapping spheres: private, social, and public. Citizens may deal with the impact of digitization within their private lives, for instance, by using e-health devices to keep better track of their health or by rejecting the use of WhatsApp out of privacy concerns. Citizens may also deal with the impact of digitization within their social sphere. For instance, by contributing to an online community such as Wikipedia or using apps to help members of their local neighborhood. Finally, citizens may deal with the impact of digitization within the public sphere by, for instance, protesting for net neutrality or voting for a politician who strives for better Big Tech regulations. By acting from within these three spheres, citizens can impact the role of digital technology in society and contribute to its governance (Gardenier et al., 2024).

The goal of distinguishing these different spheres of technological citizenship is to move beyond a single, normative vision of participation—the idea that only one form is “good.” Instead, this framework highlights the diverse ways citizens contribute to shaping the digital society, whether in their private lives, social communities, or the public sphere, recognizing each as different, but equally valuable. This allows for investigating the roles of citizens in shaping the digital society while not being confined exclusively to formal ways of citizen participation such as voting or top-down organized public engagement initiatives.

Like “scientific citizenship” (Davies, 2015), technological citizenship is widespread and not confined to specific participatory spaces. Davies’ concept of scientific citizenship accounts for moments when citizens negotiate the role of science and technology in society, which may materialize at science fairs and maker spaces. Similarly, technological citizenship includes material interactions with technology at home, work, and with friends and family. These interactions across private, social, and public spheres constitute moments of technological citizenship. This idea aligns with Ruha Benjamin’s “viral justice” (Benjamin, 2022), where small, everyday actions collectively lead to significant social change. Similarly, every interaction of citizens with technology has its effect, and taken together may effectuate broader change. In sum, citizens’ interactions in their private, social, and public lives contribute to shaping the role of digital technology in contemporary democratic society.

The goal of this approach is to understand the broader context of the challenges of digitization and strengthen citizens’ ability to address them. In the case of hackers, it does not focus on creating new or better forms of citizen participation in cybersecurity but rather enables understanding the existing cybersecurity system and recognizing where citizen participation already takes place, and how citizens’ constructive roles can be strengthened.

## **2.2. Institutions Supporting or Constraining Citizen Participation**

The hackers discussed in this article currently make an important contribution to maintaining security in the digital society. However, they were initially not welcome to do so as they were regarded as criminals. In this case, participation by the hackers was uninvited (Wynne, 2007), and the government’s hostile stance meant that hackers would face prison sentences when they tried to address the public issue of vulnerabilities.

This case highlights that participation always takes place within social systems of inclusion, validation, and exclusion across various fora in society, such as politics, the judiciary, and the media. Institutions, and the organizations that constitute them, can constrain citizens in their ability to address issues of public concern (Giddens, 1984). Here, institutions are considered as human-made, social systems that govern the behavior of individuals within a specific domain in society, enabling certain behaviors while restricting others (Greif, 2006). Relevant institutions in this case are legislation, the judiciary, science, corporations, and the Dutch government. Participation that diverts from the norms or rules within such institutions tends to be ignored or even persecuted. For instance, individuals who expose corruption, human rights abuses, or other illegal activities within organizations or governments often face severe retaliation. Whistleblowers like Edward Snowden have faced legal action and exile for their actions.

The case highlights the necessity of recognizing forms of technological citizenship as participation, as institutions play a crucial role in enabling or constraining participation. The goal of this article is to

demonstrate vulnerability disclosure as a form of uninvited participation, to assess the role of institutions in supporting or constraining citizen participation, and to highlight the role of citizens in shaping these institutions to legitimize their participation.

### 3. Case Study: Volunteer Hackers in the Netherlands

The description of the case study aims to represent the events that occurred between 1980 and 2022 that impacted and shaped the current practice and norms regarding vulnerability disclosure in the Netherlands. Four books have been written about volunteer hackers in the Netherlands (Jacobs, 1985; Reijnders, 2023; van 't Hof, 2015, 2021), which are referred to as secondary resources. The events and other sources discussed in these books, such as court hearings, governmental debates, and parliamentary papers were analyzed in their original form.

Moreover, a systematic analysis of newspaper articles, court hearings, and parliamentary papers available online was conducted by searching for relevant terms (e.g.: hacking, hacker, vulnerability disclosure, computer) within various databases (<https://www.delpher.nl>, <https://www.rechtspraak.nl>, <https://www.tweedekamer.nl>). From the retrieved information, sources that contain information about hackers in the Netherlands who disclose vulnerabilities intending to improve cybersecurity were analyzed. Additionally, international scientific papers and reports describing events relevant to the case were reviewed. Then, based on the conducted analysis, a timeline was created composed of the events that significantly impacted the development of the practice and norms regarding vulnerability disclosure in the Netherlands. Most relevant events from this timeline were written out and divided into three periods:

- Period 1: Hackers as uninvited participants;
- Period 2: Hackers as tolerated participants;
- Period 3: Hackers recognized as crucial participants.

While there are excellent accounts of the development of vulnerability disclosure in other countries, such as the United States (Ellis & Stevens, 2022; Goerzen & Coleman, 2022), and multiple books on hacker culture and practice in the Netherlands (e.g., Jacobs, 1985; Reijnders, 2023; van 't Hof, 2015, 2021), there is no comprehensive overview of the developments that led to the current vulnerability disclosure policy in the Netherlands, and this article fills that gap.

While this case study is situated in the Netherlands, the developments are naturally embedded within a global context. Similar developments have occurred in other countries, like the United States, which have influenced the development of vulnerability disclosure in the Netherlands. These influences will be highlighted as necessary. The description of this case is, however, focused on the evolving cybersecurity context of the Netherlands—how related laws, regulations, policies, and jurisprudence came into being—and the role volunteer hackers played in these developments.

#### 3.1. Period 1 (1980–1993): Hackers as Uninvited Participants

In the 1980s, the hacker sub-culture emerged in the Netherlands, consisting of young individuals who hacked computers for fun or out of curiosity. Internet access was very expensive at the time, so hackers hacked into

networks of institutions like universities to get online (Stolwijk, 1990). During their online explorations, they discovered that many computer systems were poorly secured. On online fora and bulletin boards they shared methods to access these systems and tricks to exploit functions, allowing them to, for example, make free phone calls. Later, the “techno-anarchist magazine” Hack-Tic was founded, reporting on successful break-ins into poorly secured computer systems and offering a platform to share tricks with others in the community (Gonggrijp et al., 1989).

While some hackers were motivated by fun, others had more ideological reasons. Inspired by hacker communities in the United States (Levy, 1984) and West Germany, some saw how computers and the internet could benefit democracy by providing freedom of information and communication (Groenteman, 2006). For example, in the Netherlands, it was emphasized that the emerging internet was a public space that users were expected to take a part in shaping (Reijnders, 2023; Rustema, 2001; Stikker, 2019). Consequently, a Dutch hacker criticized the high costs that made the internet inaccessible to the general public: “Many of these large networks were set up with government funds and then made inaccessible to a large part of the population due to high usage costs” (Stolwijk, 1990, translation by the author).

Many hackers also recognized the risks of storing personal information on computers. They criticized how carelessly users handled confidential information and how easily government and corporate systems could be breached (Gonggrijp et al., 1989; Reijnders, 2023). The fact that these systems were so easily accessible, and that “boys as young as 13 could freely roam a million-dollar network” (Stolwijk, 1990, translation by the author) was seen as unacceptable by these hackers.

Hackers saw breaking into systems as a way to highlight this poor security. Often, gaining access did not involve much; sometimes, guessing common passwords was enough (Jacobs, 1985). A prominent hacker summarized their work: “What we do is in the public interest, even if our motivation is usually different” (Stolwijk, 1990, translation by the author). They understood that exposing vulnerabilities was beneficial to the public, even if it wasn’t always their primary motivation.

In the Netherlands in 1985, about 20 computer hackers were active, behaving as “gentleman burglars” (“Kraken van computers kinderspel,” 1985, translation by the author) who did not misuse the information they illegally obtained but reported the vulnerabilities to the affected parties. Some of their hacks, like the one at the Dutch Postal Service, made big news. In this case, the hackers did not misuse the data, which could have caused significant financial damage. The postal service praised the “neat way the gentlemen handled it” (Schmidt, 1985, translation by the author) and decided to improve their security.

However, most hacked parties, often companies, did not take vulnerability reports seriously and did not improve their security (Reijnders, 2023). For this reason, hackers often sought publicity to draw attention to vulnerabilities and pressure companies to take security more seriously. This approach, later known as “full disclosure” (Goerzen & Coleman, 2020), was not well received by the hacked parties, as it caused reputational damage and made the company more vulnerable because others could exploit the vulnerabilities as well. During this period, Dutch companies also suffered from computer fraudsters: hackers who exploited systems for personal gain (Jacobs, 1985). Despite this, many companies did not report hacks, as it would not generate good publicity and because hacking was not illegal at the time.

In 1985, hackers hacked the National Institute for Public Health and the Environment. This was the first time it became publicly known that a Dutch government institution had been hacked. The hackers had accessed sensitive patient information. The hacker who publicized the hack said he wanted to prove that citizens' privacy was not sufficiently protected ("Computers Philips en RIVM gekraakt," 1985). This hack caused political upheaval, and the minister of justice took a tough measure: He promised that hacking would be criminalized (Reijnders, 2023; Schmidt, 1985).

Reactions to this proposal varied. Some argued that as society becomes increasingly dependent on computer systems, it is important to regulate their use and misuse properly (Stolwijk, 1990). However, there was also criticism: Wasn't the real problem that companies took too few security measures? These measures were available but often expensive and not prioritized. Wouldn't it be better to solve this issue rather than criminalize hacking?

Hackers received support from the academic world. Computer science professor Israël Samuel Herschberg from Delft University regularly sought publicity to argue that these hackers were not criminals; in fact, they did good work by identifying insecure systems ("Computers vaak zo lek als een mandje," 1987). According to Herschberg, these hackers worked according to an ethic: They reported the vulnerability to the owner, gave them time to fix it, and only sought publicity if that failed. Herschberg also argued that hacking was the only way to get companies to improve their security. Academics tried to bring this to the fore through scientific publications but without success. From an academic perspective, hacking was seen as a legitimate way to disclose vulnerabilities.

In the United States at that time, the media increasingly reported on spectacular computer crackers, who became the public face of the hacker community (Jordan, 2008; Nissenbaum, 2004). As a result, the term "hacker" acquired a negative connotation and became increasingly associated with computer users who broke into computer systems by exploiting vulnerabilities (Oliver & Randolph, 2022). Following the example of the United States, which began taking tougher action against hackers from 1990 onwards—such as the arrest of hacker Kevin Mitnick, who was portrayed in the media as a "life-threatening genius" (Reijnders, 2023) and held in pre-trial detention for five years; and Operation Sundevil, which cracked down on illegal computer hacking (Goerzen & Coleman, 2022)—the climate in the Netherlands also became stricter. After an extensive eight-year-long legal process and heated parliamentary debates, in 1993 the Computer Crime Act was introduced (Koops, 2005). The maximum penalty for hacking or "computer trespassing" was four years' imprisonment or a fine of €11,250 (Koops, 2005). Nowadays, the maximum penalty for computer trespassing in the Netherlands is a fine of €22,500 and four years' imprisonment.

### **3.2. Period 2 (1993–2018): Hackers as Tolerated Participants**

Shortly after the introduction of the Computer Crime Act, the first hacker in the Netherlands was prosecuted. Although the hacker did not cause any direct damage, he did cause inconvenience because the system had to be reconfigured ("Computerkraker voor de rechter," 1995). He was held in pre-trial detention for 38 days and sentenced to a six-month suspended prison sentence and a fine of 5,000 guilders (€2,200; "Nederlandse rechtbank vonnist," 1993; Reijnders, 2023).

The new law marked the end of an era for many hackers who had been freely exploring computer networks. Some took concrete measures, such as setting up an internet service provider so they no longer had to hack

to access the internet. One of the founders later described the establishment of this provider as “an initiative to avoid ending up in prison” (Groenteman, 2006, translation by the author). This internet provider, named XS4ALL, continued to operate as a reputable provider until 2019 and played a significant role in making internet access available to the general public (Reijnders, 2023).

However, the hacker subculture began to fade. The magazine Hack-Tic was discontinued in 1995. Some hackers quit hacking because they then faced prison sentences. Others continued to hack but did so in secret (“Lastig Hack-Tic houdt op op papier te bestaan,” 1995). For example, hackers would anonymously disclose a vulnerability in collaboration with a journalist, sometimes after first warning the hacked party. This practice would later become known as “responsible disclosure” (RD).

This period thus begins with the criminalization of hacking. However, due to a multitude of developments in various institutional arenas, the value of disclosing vulnerabilities for cybersecurity is reconsidered during this period, making it possible for hackers, to some extent, to continue disclosing vulnerabilities. In the following subsections, I will discuss these developments and the impact they have had.

### 3.2.1. Lawsuit Casts a Positive Light on Vulnerability Disclosure

Within computer science, vulnerability testing remained a legitimate research method. In 2008, researchers from the Dutch Radboud University found a vulnerability in a chip created by the Dutch company NXP that was used worldwide in access systems to buildings and public transport, such as the London metro and Dutch trains. The researchers wanted to publish this vulnerability at a scientific conference to warn about the insecurity of the chip. Moreover, they wanted to demonstrate that the security principle that NXP used in this chip was flawed. Seven months before the planned publication, the researchers contacted NXP to report the leak so that NXP could fix it. NXP appreciated the vulnerability report, but wanted to prevent publication and, therefore, filed a lawsuit against the researchers (Rechtbank Arnhem, 2008; van ‘t Hof, 2015).

NXP argued that the publication of the article should be prevented because it would harm NXP and cause serious societal and security problems, as it would enable others to crack the chip as well. The researchers argued that the article’s publication falls under the freedom of expression protected by the European Convention on Human Rights and should therefore not be stopped. The judge concluded that the security risks were caused by NXP’s unsafe chip, not by the fact that researchers would publish the vulnerability. Moreover, the judge stated that publicizing vulnerabilities is in the public interest. The publication could, therefore, continue.

The judge’s ruling was a legal milestone (van ‘t Hof, 2015) that changed the perspective on vulnerability disclosure: The judge allowed the publication of a vulnerability discovered by hacking based on the right to freedom of expression and the promotion of the public good (Rechtbank Arnhem, 2008). This court ruling placed the hackers/researchers in a new role, equivalent to that of a whistleblower or journalist. With this ruling, the societal value of disclosing vulnerabilities—at the expense of financial and reputational harm for the ICT vendor—was established in the Dutch jurisprudence.



### 3.2.2. Companies and Hackers Start to Collaborate

Also in the rest of the world, hackers continued to detect vulnerabilities. In the United States, the computer industry increasingly started to understand the value of hacking techniques, like full disclosure, and hackers themselves (Goerzen & Coleman, 2022). Yet, hackers continued to face the risk of legal repercussions. Therefore, in 2009, American hackers started the “No More Free Bugs” campaign to initiate consultations for better compensation and recognition for hackers who voluntarily disclose vulnerabilities (Ellis & Stevens, 2022). As a result, American companies set up “bug bounty” programs, allowing hackers to receive a financial reward after disclosing a vulnerability. In addition, companies introduced RD policies. RD refers to the practice of reporting a vulnerability directly to the affected party so that it can be fixed before publication. Companies with an RD policy invite hackers to find vulnerabilities in their systems, and if hackers follow their guidelines, the company pledges not to press charges. In 2012, Dutch telecom companies were the first to adopt an RD guideline.

While in the United States, the commercialization of vulnerability disclosure flourished, in the Netherlands, reporting vulnerabilities retained its voluntary nature for a time. Hackers usually did not receive a financial reward, but a public “thank you” and a t-shirt instead. If hackers disclosed a vulnerability in a government ICT system, for instance, they would receive a t-shirt saying “I hacked the Dutch government and all I got was this lousy t-shirt” (van ‘t Hof, 2015). However, recently also in the Netherlands, the commercial bug bounty practice is gaining ground, with bug bounty platforms like Intigriti.

### 3.2.3. Cyber Crisis Launches Cybersecurity on the Political Agenda

Meanwhile, the role of hackers in Dutch cybersecurity governance received political attention. In 2011, the Diginotar hack took place in the Netherlands, which was considered a “wake-up call” (Dutch Safety Board, 2012) that launched cybersecurity on the political agenda. In this hack, the Dutch company Diginotar, which issues certificates for websites, was hacked, and the reliability of a wide range of websites in the Netherlands was no longer guaranteed. The hack was claimed by an Iranian hacker (Wollaars & Kaboly, 2011). This caused a major political stir in the Netherlands because a hack with such a concrete effect had never occurred before (van der Meulen, 2013).

This crisis led, among others, to the establishment of the National Cyber Security Centre, which had as its aim coordinating national cyber threats. This crisis also encouraged politicians to reconsider the role of volunteer hackers in promoting cybersecurity. A member of parliament asked: “Is the minister prepared to investigate how the government can improve the security of its computer systems with the expertise of hackers, without the hackers suffering legal consequences?” (Tweede Kamer, 2011, translation by the author). The minister of security and justice promised that this would be investigated (Tweede Kamer, 2012).

### 3.2.4. The Government Introduces a Tolerance Policy for Hacking

In 2013, the Dutch government took the first step in the drawing up of new policy regarding vulnerability disclosure: the RD guideline (National Cyber Security Centre, 2013). The guideline explained how companies can draw up an RD policy to promote cooperation with hackers. It was based on existing RD policies of companies in the Netherlands and was essentially an encouragement of self-regulation between hackers and companies.

By publishing this guideline, the Dutch government took a position: “Ethical hacking” positively contributes to society and this should be encouraged instead of punished. The Netherlands was the first country in the European Union to draw up a national RD policy (European Union Agency for Cybersecurity, 2022). Yet, the guideline was negatively received by the hacker community because the law for computer trespassing remained intact (de Winter, 2013; Hoepman, 2013). As such, the responsibilities of hackers and companies were out of balance: Hackers were only allowed to report vulnerabilities to companies with their own RD policy, while companies were only encouraged and not obliged to have such a policy set up—thus, hackers often still faced a risk of being prosecuted. As a result, the initial problem of unattended vulnerabilities remained effectively unresolved.

### 3.2.5. Lawsuit as a Breeding Ground for RD Principles

In a criminal case in 2013, the jurisprudence regarding vulnerability disclosure was further developed. In this case, a patient of a health institution noticed the (weak) password of a doctor (van ‘t Hof, 2015). The password gave access to the computer system which contained sensitive patient data. The patient reported the security breach to the institution, but he did not receive a—in his opinion—quick response, after which he reported the leak to the media. He invited a local television broadcaster and he downloaded (anonymized) patient data as evidence. After publicizing the leak, the healthcare institution pressed charges against this “hacker” and the case appeared in court (Rechtbank Oost-Brabant, 2013).

The central question in the lawsuit was: Was this patient a whistleblower and did he serve the public interest by reporting this leak to the media, or did he go too far? The judge stated that three principles are important to assess whether the hacker disclosed the security breach responsibly: Did he act in the public interest? Did his action comply with the proportionality principle, i.e., did the suspect not go further than was necessary to achieve his goal? And did his action comply with the subsidiarity principle, i.e., were there no other, less far-reaching ways to achieve the goal? According to the judge, the hacker met the first principle: He served the public interest with his disclosure. However, he did not comply with the last two principles: The hacker could have given the organization more time to respond to the vulnerability report before disclosing the breach publicly, and he did not have to download patient data to report the vulnerability successfully. Therefore, the hacker received a fine of €750.

After this ruling, the principles of public interest, proportionality, and subsidiarity were adopted by the Public Prosecution Service in their policy on how to deal with “ethical hackers” (College van Procureurs-Generaal, 2013). Within a criminal investigation, these three principles formed the assessment framework for a “responsible disclosure.” The minister of justice announced two years later that no hackers had been prosecuted whose hack complied with these principles since 2013 (Tweede Kamer, 2015a), and available court cases verify this until 2022.

### 3.2.6. New Governmental Policy Balances the Responsibilities Between Companies and Hackers

In 2015, the House of Representatives criticized government policy, defending that hackers should be able to report vulnerabilities to companies without their own RD policy (Tweede Kamer, 2015b). After the evaluation of the national RD policy in 2015, which concluded that RD contributes to strengthening the digital resilience of the Netherlands (Tweede Kamer, 2015a), and discussions with the hacker community

(Tweede Kamer, 2018), an updated version of the policy was published in 2018. The original name “responsible disclosure,” indicating the responsibility that hackers must take to report vulnerabilities, was adapted to “coordinated vulnerability disclosure” (CVD), emphasizing the fact that both parties, the hacker and the recipient, must handle communication about the vulnerability responsibly. The principles of public interest, proportionality, and subsidiarity were included in the policy. If a hacker reports a vulnerability to an organization and works according to these principles, the hacker is not punishable, even if a company does not have its own CVD policy.

At this time, the combination of governmental policy and jurisprudence made vulnerability disclosure without facing punishment possible again—to a certain extent. The law against computer trespassing continued to exist, but because sufficient jurisprudence had been developed, hackers who hack according to the CVD principles did not have much to fear in court. The Dutch policy is, therefore, a tolerance policy, a form of “positive eliciting” (Harms, 2017, p. 1): Hacking is allowed, and hackers are encouraged to do so, provided they act according to the CVD principles.

### **3.3. Period 3 (2018–2022): Hackers Recognized as Crucial Participants**

The new national policy and jurisprudence provided new possibilities: Hacking was allowed if hackers adhered to the CVD principles. As a result, hackers started to act in accordance with these principles. By doing so, they claimed a legitimate role in cybersecurity governance.

In 2019, the Dutch Institute for Vulnerability Disclosure (DIVD) was founded. DIVD is an organization of volunteers who scour the internet for vulnerabilities. DIVD hackers structurally violate the Computer Crime Act when they search for vulnerabilities. But because they work according to a code of conduct that includes the CVD principles, they avoid prosecution. Furthermore, being part of an established community increases the chance that a receiver of a vulnerability report takes the breach seriously (van ‘t Hof, 2021, p. 217).

In recent years, DIVD and other volunteer hackers have played a central role in Dutch cybersecurity governance. Notably, there are gaps within formal Dutch cybersecurity governance: There is no central desk for receiving and sharing information about security threats with all affected parties. The National Cyber Security Centre coordinates and shares security threats, but its mandate is limited to “vital” companies and organizations, such as electricity and water suppliers. Consequently, non-vital companies and smaller organizations do not receive crucial cybersecurity information, putting them at a disadvantage. Additionally, the distinction between vital and non-vital companies is becoming increasingly blurred due to chain dependency.

Volunteer hackers fill this gap by scanning organizations for vulnerabilities and personally notifying them when their systems are vulnerable. In 2019, DIVD security researchers played a crucial role in a major cybersecurity crisis by directly notifying the organizations that were at risk of being attacked (van ‘t Hof, 2021). Also, DIVD is setting up an academy in which novice hackers can learn the skills of hacking according to the CVD guidelines.

Volunteer hackers now have a unique role in the cybersecurity network and they are tolerated when they hack to find vulnerabilities if they adhere to the CVD principles. The role of volunteer hackers in maintaining cybersecurity is increasingly recognized by the Dutch government. The Dutch Safety Board concluded in their investigation of a major cybersecurity incident caused by the Citrix vulnerability in 2020 that “volunteer

security researchers played a crucial role in incident response” (Dutch Safety Board, 2021, translation by the author). The role of volunteer hackers was also repeatedly referred to as crucial and indispensable during debates in the Dutch parliament (Tweede Kamer, 2022a). Since 2022, DIVD has received a temporary subsidy to strengthen cyber resilience in non-vital sectors.

However, the government also recognizes that the contribution of these hackers is voluntary and, therefore, not structurally guaranteed (Dutch Safety Board, 2021). Members of parliament have called for a more formally embedded role of volunteer hackers in cybersecurity governance (Tweede Kamer, 2022a). However, formalizing volunteer hacker communities would not be beneficial, as it would prevent them from continuing their activities. A government organization cannot actively scan for weaknesses without a legal basis (Tweede Kamer, 2022a). Consequently, members of parliament requested the government to set up a multi-year subsidy scheme to structurally finance “ethical hacker collectives” (Tweede Kamer, 2022b).

As of 2022, volunteer hackers who search for vulnerabilities have secured a central role in the Dutch cybersecurity landscape. They are supported by government policies and legal precedents. This new role of hackers as allies is now firmly established within the cybersecurity community. However, the government is currently figuring out how to ensure their voluntary contributions, as Dutch cybersecurity has become partially dependent on their efforts.

#### 4. Discussion

This case study has shown the role of Dutch volunteer hackers in the development of the Dutch vulnerability disclosure policy. Since the 1980s, hackers have aimed to make the internet safer by exposing vulnerabilities. Initially, the Dutch government viewed hacking as inherently illegal, which hindered these efforts. Hackers’ contributions were not accepted as a form of participation, and the government criminalized hacking, positioning hackers as part of the problem. However, over time, the government’s and other stakeholders’ perspectives shifted. Today, the contributions of volunteer hackers to cybersecurity governance are recognized and encouraged, albeit to a limited extent.

The hackers described in this case study can be seen as part of a public emerging to address collective concerns. Hackers’ activities represent a form of material participation (Marres, 2012). Through their interactions with digital technologies in private, social, and public spheres, these hackers have played a central role in addressing cybersecurity vulnerabilities, showcasing technological citizenship. Hackers highlighted the importance of cybersecurity across political, corporate, scientific, and public agendas, prompting solutions from the government and private sector. While some hackers may have had political motivations, many hackers disclosed vulnerabilities for personal development, a sense of justice, satisfaction in finding flaws, collaboration or competition with others, or peer recognition (Jordan, 2008; Weulen Kranenbarg et al., 2018). Despite their varied motivations, these hackers’ actions over the past 40 years have had political impacts. Each hack to disclose vulnerabilities has contributed to raising awareness about the importance of cybersecurity. By disclosing vulnerabilities, the hackers have initiated discussions on responsibility and accountability for securing digital systems, making their private acts have public consequences.

By moving between private, social, and public spheres, the volunteer hackers navigated hostile institutions. Depending on their goals and context, they could disclose vulnerabilities either directly or publicly. Public

disclosure aimed to raise awareness and exert pressure on the affected party to take action, particularly if no measures had been implemented. In contrast, direct disclosure was most effective when there was strong collaboration with the recipient, such as companies with established RD or CVD policies, or when national policies and legal frameworks permitted it.

Further, the hackers united around shared goals to strengthen their position against hostile stakeholders, forming a social community. Although campaigns such as the “No More Free Bugs”—which raised awareness about the unfair treatment volunteer hackers faced from the private sector—took place in the United States, they impacted developments in the Netherlands. By establishing DIVD, hackers leveraged national policies and legal frameworks under CVD principles. DIVD hackers addressed security gaps left by the Dutch government and private sector, exemplifying technological citizenship in the social sphere where citizens tackle issues neglected by the government and market (Gardenier et al., 2024). These hackers organized to address societal cybersecurity gaps overlooked by companies and government agencies. Cybersecurity companies often miss threats to civil society (Maschmeyer et al., 2020), and the National Cyber Security Centre focuses only on vital infrastructure, leaving many organizations unprotected. These volunteer hackers filled this gap. Through community building and active engagement, these hackers have gained credibility among other cybersecurity stakeholders, enabling them to continue disclosing vulnerabilities on a national scale. With the bug bounty industry gaining ground in the Netherlands, these hackers can also increasingly take on this role with financial incentives.

In summary, this case illustrates that participation in the digital age spans private, public, and social spheres, with citizens navigating these realms based on their goals and hostile or supportive institutional elements.

#### ***4.1. Vulnerability Disclosure Enabled or Constrained by Institutional Arrangements***

The case study further illustrates how institutions can enable or constrain citizen participation (cf. Giddens, 1984). As shown here, participation can be uninvited (Wynne, 2007) and may face obstacles if not recognized or endorsed by institutions. Institutions govern the behavior of individuals within a specific domain in society, enabling certain behaviors while restricting others (Greif, 2006). The institutions of legislation, the judiciary, science, and government have all played a role in regulating the behavior of hackers in this case. Some institutions constrained hacking in certain periods, while other rules enabled hacking under certain conditions in later periods. Table 1 provides an overview of how particular institutions regulated the behavior of hackers over different periods.

During the first period, hacking was new and emerging, not confined by any policies or laws, allowing hackers to operate freely. In the second period, hacking was criminalized, and hackers faced severe restrictions on their ability to disclose vulnerabilities, making it nearly impossible for them to continue their work without risking prison sentences or fines. The prospect of a legal sanction deterred hackers from continuing to hack after it was criminalized in 1993. This impeded the practice of vulnerability disclosure, even though hackers and computer scientists recognized its value for maintaining cybersecurity as early as the 1980s. In the third period, hacking became legitimized under certain conditions, enabling hackers to continue addressing collective issues by disclosing vulnerabilities. This demonstrates that institutions can both constrain and enable citizens to deal with the opportunities and risks of digitization.

**Table 1.** Overview of how institutions regulated the behavior of hackers.

Period	Hostility or support by institutions	Behavior by hackers
1	Hacking is first unseen, and later criminalized by the Dutch government. Within the computer science community, disclosing vulnerabilities is seen as a legitimate practice.	Hackers find and disclose vulnerabilities.
2	Hacking is criminalized, but the public value of vulnerability disclosure is recognized through court cases, the collaboration between hackers and the private sector, and a cybercrisis that generated awareness for cybersecurity. This leads to new government policy that tolerates hacking under certain conditions.	Some hackers quit hacking, others continue to disclose vulnerabilities, but in secret.
3	The Dutch government recognizes hackers as crucial participants in cybersecurity governance and searches for structural support.	Hackers find and disclose vulnerabilities according to CVD principles.

#### **4.2. Hackers Playing a Central Role in Legitimizing Their Participation**

Importantly, hackers played a central role in legitimizing their participation by influencing the change of rules and norms within institutions. They engaged across private, social, and public spheres, interacting with various institutional organizations—including legislators and the private sector—to shape vulnerability disclosure as a legitimate form of citizen participation.

In the second period, the Dutch government’s hostility towards hackers diminished as the societal impact of vulnerabilities and the crucial role of hackers in addressing them became clear. Over time, institutional arrangements that initially rejected vulnerability disclosure evolved. Notably, the Dutch government was not the primary driver of these changes. This shift resulted from developments and interactions among various institutions, including the judiciary, the private sector, science, and the parliament. Hostility towards hackers faded as stakeholders increasingly recognized the societal value of vulnerability disclosure: Private sector companies began collaborating with hackers, and vulnerability disclosure remained a legitimate research area in computer science. The judiciary’s recognition of vulnerability disclosure as a public good marked a pivotal shift in legitimizing hackers’ contributions. Additionally, a disruptive cyber crisis further shifted the government’s perspective on vulnerability disclosure.

This evolution aligns with the systemic approach to deliberative democracy, which assumes that deliberation, democratic engagement, and legitimacy are distributed across various societal fora, including legislatures, companies, universities, voluntary organizations, and the judiciary (Mansbridge et al., 2012). It highlights that the state is not the sole agent in certifying or rejecting participation; other institutions also play a role in the legitimization process. The case demonstrates how multiple stakeholders jointly shaped the practice of vulnerability disclosure into a new and responsible form of citizen participation. Eventually, the Dutch government, the private sector, and the hacker community shaped norms around vulnerability disclosure to benefit the public good and foster technological citizenship. They explored how hacking could strengthen cybersecurity while acknowledging the dangers posed by malicious hackers, who are, after all, the security risk. Even well-meaning hackers sometimes caused harm by publicly disclosing vulnerabilities, possibly further damaging the vulnerable party. Therefore, it was essential to establish norms to guide vulnerability disclosure and make it a responsible practice.

Hackers' participation over 40 years has had various effects. Politics, policymaking, technology development, cybersecurity crises, corporate perceptions of hackers, and the judiciary have all influenced what counts as "participation" in Dutch cybersecurity governance. This does not mean that before government policy on vulnerability disclosure, hackers were not "participating," or that their hacking before RD principles was not "responsible." Importantly, by examining the various ways hackers participate and the role of institutions in either supporting or limiting their actions, it becomes evident that their involvement is shaped by how institutions—such as politics, the judiciary, and science—either include, validate, or exclude citizens, all within the context of ongoing technological advancements. As this case demonstrated, citizens play a crucial and mutually shaping role in these developments, particularly concerning issues like vulnerability disclosure. They drive new forms of participation to address collective issues, actively influencing how these issues are understood and acted upon. Through their interactions with technology in private, social, and public spheres, citizens influence the role of digital technology in society. It is essential that these diverse forms of citizen participation are recognized and supported by institutions, enabling citizens to address their concerns and, in doing so, promote democracy in an increasingly digital world.

How, in this case, could volunteer hackers be further supported? The Dutch government is currently searching for a way to structurally back hackers' participation to ensure the cyber-security of the Netherlands, given the country's partial reliance on their efforts. However, this case demonstrates that institutionalizing hackers—by making them a state entity—would undermine the initiative itself. The effectiveness of hackers in their current role relies on their independence and volunteer nature. Rather, institutional support that can take various shapes or forms is necessary to ensure the endurance of this form of voluntary citizen participation.

The role of hackers could be strengthened by finding ways to support their independent and voluntary work. Legal frameworks regarding hacking could be adjusted to ensure that disclosing vulnerabilities is not treated as a criminal offense, thus alleviating the legal risks hackers still face. For example, research into security vulnerabilities could be framed as a right, accompanied by a responsibility to disclose findings in a manner that enhances information security (van Daalen, 2022). Additionally, promoting the practice of CVD within the hacking community could encourage novice hackers to follow CVD guidelines, inspired by positive peer examples (Weulen Kranenbarg et al., 2018). Policymakers could also support bug bounty programs based on commercial or community-driven CVD initiatives (Zrahia, 2024). With the contributions of volunteer hackers now recognized, it becomes possible to identify effective ways to support their constructive efforts to address the public interest.

## 5. Conclusion

This article has demonstrated the role of voluntary hackers in addressing ICT vulnerabilities in the Netherlands. Although hacking has been illegal since 1993, hackers who find and disclose vulnerabilities directly to ICT vendors are now tolerated and play a crucial role in Dutch cybersecurity governance. The Dutch government, the private sector, and the hacker community have collaboratively shaped the practices and norms surrounding vulnerability disclosure, making it a practice of technological citizenship that benefits the public good.

The hackers described in this case emerged as a public to address and shape the issues caused by the digitization of society through hacking. This case demonstrates that while citizens can play a vital role in tackling issues related to digitization, their contributions can remain unrecognized or constrained by



institutions. It also shows how institutions can support citizen participation when citizens' contributions to the governance of digitization are recognized. Furthermore, it emphasizes the crucial role that citizens play in shaping these institutions to legitimize new forms of participation. The case of Dutch volunteer hackers demonstrates that it is essential to acknowledge and empower citizens' contributions to the governance of digitization and enable technological citizenship in various domains to foster a resilient democratic digital society.

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## About the Author



**Anne Marte Gardenier** is a PhD candidate at Eindhoven University of Technology, focusing on “technological citizenship.” Her research examines how citizens contribute to strengthening the resilience of democratic societies in the face of digitization. By exploring the intersection of technology and civic engagement, her work aims to better understand the role of citizens in shaping the digital society.

# Migrants' Participation and Migration Governance Amidst Hostility in Small Localities: An Italian Case Study

Alba Angelucci <sup>1</sup> , Gül Ince-Beqo <sup>2</sup> , and Fabio De Blasis <sup>2</sup> 

<sup>1</sup> Department of Law and Political, Economic and Social Sciences, Università degli Studi del Piemonte Orientale “Amedeo Avogadro,” Italy

<sup>2</sup> Department of Social and Political Sciences, University of Milan, Italy

**Correspondence:** Alba Angelucci ([alba.angelucci@uniupo.it](mailto:alba.angelucci@uniupo.it))

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## Abstract

In this article we examine how small and medium-sized towns address migrants' participation amidst hostility. To do so, we focus on a small town in central Italy. We scrutinise two dimensions of participation—visibility and agency in policy-making—and connect them to specific forms of hostility towards migrants that can arise in small communities. We also consider how changes in the social fabric and political discourse can overcome and subvert such hostilities. By exploring the case vertically (involving institutions) and horizontally (involving civil society actors), we analyse local migrants' participation in light of political transitions and changes in the local government's attitude. We focus in particular on how and whether migrants are granted space in the planning and implementation of integration and participation policies across different periods in a small town in central Italy. This case highlights substantial policy transitions that shape migrants' involvement in local life and set boundaries on their engagement. The article, which is based on qualitative research conducted within the EU-funded project PISTE—Participation in Small and Medium-Sized Towns: Experiences, Exchanges, Experiments, relies on policy analysis and 17 semi-structured interviews with policy-makers and civil society actors. The results show that political discourse on migration affects perceptions and practices of hostility in regard to migrants and the forms of visibility assumed by migrants' participation in small and medium-sized towns. When participation is politically hindered, everyday practices of visibility (such as being visible in public spaces) assume political significance. The presence of “bridging figures” is crucial for facilitating the transition from an adverse to a more inclusive political environment, enhancing participation by specific migrant groups. However, reliance on such bridging figures and personal relationships can be a double-edged sword. It can promote participation, but it may confine it to individual interactions rather than foster broader migrants engagement.

## Keywords

bridging figures; hostility; local policy-making; migrants' participation; migration policies; political participation; small towns

## 1. Introduction

This article explores migrants' participation in the policy-making process in the face of hostility in small and medium-sized towns (SMTs). For this purpose, it uses a case study focused on a small town in central Italy. It contributes to the debate about new, emerging forms of migrants' participation in policy-making processes and inclusion in civic and political life amidst hostility at the local level in SMTs (Bonizzoni & Marzorati, 2015; Schiller, 2023), integrating into this debate the socio-spatial and relational dynamics in which these practices are embedded. By adopting an integrated approach to both vertical and horizontal dynamics, this study examines policy and institutional relations across different governance levels, alongside the formal and informal interactions between institutional actors and other stakeholders. This dual analysis underscores how and why emerging forms of migrants' participation are interconnected with the socio-spatial and relational dynamics in which these forms are embedded, highlighting that they are inseparable in understanding the complexities of migrants' participation and inclusion in SMTs.

In doing so, the analysis adopts a complex notion of participation able to highlight its multifaceted character. We distinguish and consider both the political and civic dimensions of participation. Whilst these two dimensions are practically and analytically distinguishable, their impacts on the emergence (as well as the overcoming) of hostility towards migrants at the local level are intertwined, overlapping, and mutually influencing.

The focus on the political dimension of participation enables us to explore the local implications of how changing forms of representation affect migrants' participation in the policy-making process. This examination also helps us identify emerging political actors, all within the context of a significant political shift at the local level in our case study. Indeed, the case analysed also reveals its own peculiarity in terms of the evolving policy understanding of migrant participation in its different forms, so it is an intriguing example for studying the implications of the shift in political participation and representation of migrants at the local level. This shift has a direct impact on the forms of hostility that migrants experience. It shapes their interactions with local institutions and influences their ability to engage in the civic and political life of their communities.

The civic dimension of participation is explored through a socio-spatial lens which highlights the interactions and connections between local spatial configurations and the practices of exclusion/inclusion. Specifically, we examine how public space is perceived and experienced by both the migrant community and native residents. This includes investigating whether and how accessibility to public spaces becomes a contentious issue between migrants and the local administration. This approach enables us to uncover the forms of hostility directed towards migrants in and through these spaces, as well as the strategies that both migrants and other actors employ to overcome these tensions and foster a more inclusive environment.

How political and civic participation occurs will be disentangled in order to underline two intertwined processes that have been relatively underexplored in the literature on SMTs: the transformation of forms of



participation and representation; and the emergence of new policy entrepreneurs of foreign origin within local administrations. The intertwining of these processes has produced transformative outcomes in local policy-making and integration policies, contributing to the development of a distinctive “mode” of participation in policy-making specific to SMTs. The article seeks to unravel and critically assess this mode of participation, highlighting its strengths, weaknesses, and its innovative potential as a means to counteract hostility and promote inclusion.

The rest of this article starts with a theoretical introduction aimed at positioning this study in the scholarly debate on participation and inclusion at the local level, specifically addressing these issues in the context of SMTs. Then, after the context and the methods of the analysis have been described, the results of the fieldwork will be presented, lingering on two intertwined dimensions related to migrants’ participation at the local level: (a) the institutional approaches to the “visibility” of diversity in public space; and (b) the emergence of new actors in the participatory realm able to foster specific dynamics and to smooth inclusive processes. These two steps of the analysis therefore focus on an intermediate level between the formal and informal practices of participation. They particularly stress the distinctive features of the small context of our case study, opening up to the definition of a specific “mode” of participation at local scale in SMTs that this article tries to describe and disentangle in regard to its strengths, weaknesses, and innovative potential.

## 2. Analysing Migrants’ Participation in SMTs: Theoretical and Conceptual Background

In the Global North, the “local turn” in the implementation of policy measures and interventions regarding migration and migrants’ participation (Ambrosini & Boccagni, 2015; Barberis & Angelucci, 2022; Penninx & Martiniello, 2004) entailed the delegation of juridical and administrative responsibilities for these issues to lower tiers of governance. This enabled local actors to operate within discretionary spaces—ones often unaddressed by national frameworks—and to define and implement local policies that might complement, exceed, or even oppose regional or national directives (Dimitriadis et al., 2021; Joppke, 2017). Over the past two decades, as small towns have seen an increase in their foreign populations amid declining local demographics, traditional balances in regard to the coexistence of different groups and social cohesion in these places have shrunk, creating new forms of hostility towards migrants. As the increasing visibility of migration becomes a political issue impacting social cohesion in these areas, local administrations are often caught between managing this growing diversity and countering the rise of anti-immigrant sentiments.

Recently, an interesting strand of research in political science and sociology (Caponio & Pettrachin, 2024) has focused on migration and integration in SMTs by investigating community dynamics of inclusion from a cross-national and comparative perspective. SMTs, unlike larger cities, often lack the established frameworks, resources, and historical experience with which to effectively manage diversity; a lack which creates unique challenges in both policy implementation and social cohesion. This distinctiveness has made SMTs intriguing cases for understanding how smaller communities address issues of migrants’ participation in local policy-making and integration into civic and political life.

In the context of Italy, this perspective has highlighted the pivotal role that local actors play in managing diversity and addressing the needs of vulnerable groups (Angelucci, 2023). Furthermore, it has enabled scholars to underline the heterogeneity of policy-making approaches on the local level and the importance of local actors (including migrants and migrants’ representatives) in determining different policy outcomes.



On the one hand, many SMTs have implemented hostile, exclusionary, and discriminatory policies in regard to migrants (Ambrosini, 2013; Gargiulo, 2017; Marchetti, 2020; Marzorati & Semprebon, 2018). On the other hand, inclusive policies and practices, such as those related to the reception of refugees and asylum seekers, have been fostered in some small towns by various factors: the favourable attitudes of local administrations; blurred boundaries between the public sector and third sector; ease of access for the local population to institutions and policy-makers; and the activation of NGOs and key individuals (Dimitriadis & Ambrosini, 2024; Semprebon et al., 2022).

Recent studies have highlighted how several factors influence local migration governance. These include the population's and the administration's political orientation, the role of NGOs and civil society, and key individuals who can act as "boundary spanners" or "policy entrepreneurs" (Ahmed, 2020; Garcés-Mascreñas & Gebhardt, 2020; Mintrom & Norman, 2009; Schammann et al., 2021). Indeed, in SMTs, where such roles are often filled by a single individual, interactions with migrant groups may be highly personal or even intimate. While this can foster meaningful engagement, it may also create a potential vulnerability, because the participation of migrants may become overly dependent on the efforts of one person. These dynamics directly affect migrants' civic and political participation, either mitigating or exacerbating hostilities in SMTs.

In this article we consider participation in a broad sense that encompasses both the political dimension, linked to shifts in local political orientation and representation, and the civic dimension, which refers to any social action aimed at fostering social change (Cognetti, 2022). In particular, the civic dimension is dealt with by specifically focusing on local network actors as situated in particular socio-spatial configurations in order to highlight local dynamics and coping strategies with respect to the proliferation of social and political environments hostile to migrants in SMTs. In other words, civic participation is understood as occurring in specific places, such as main squares and other public areas commonly used in various ways and for different purposes by local citizens. The focus on spatiality enables the analysis to highlight the unique scale of SMTs in regard to the civic dimension of participation, given that civic participation—whether it occurs or not—reflects the degree of hostility or openness towards migrants. The specific (small) spatial context influences both the visibility and the agency of migrants in these public spaces. At the same time, the political dimension is particularly significant at the local level, where it can take many forms. It is shaped (and often restricted) by legal and institutional frameworks, socio-economic status, and other contextual factors, including the prevailing social and political climate and the willingness of local administrations to engage in dialogue and participatory processes.

These two dimensions of participation—political and civic/spatial—directly influence migrants' participation in the policy-making process and the creation of either hostile or inclusive social environments. By adopting this dual perspective, we aim to highlight two interconnected aspects of migrants' participation in policy-making in SMTs.

The first is that the implementation of participatory processes unfolds within inherently political frameworks, where power dynamics between institutions (especially in terms of decision-making capacity) and various categories of citizens are at play. Drawing on Martiniello (1997, 2005), we distinguish between informal and formal political participation. Informal participation comprises actions such as protesting, signing petitions, and joining trade unions, advocacy groups, or self-organised groups. Formal participation concerns involvement in elections, systems of representation, and alternative mechanisms set up by local

governments, such as advisory councils specifically created to engage migrants excluded from voting by national legislation.

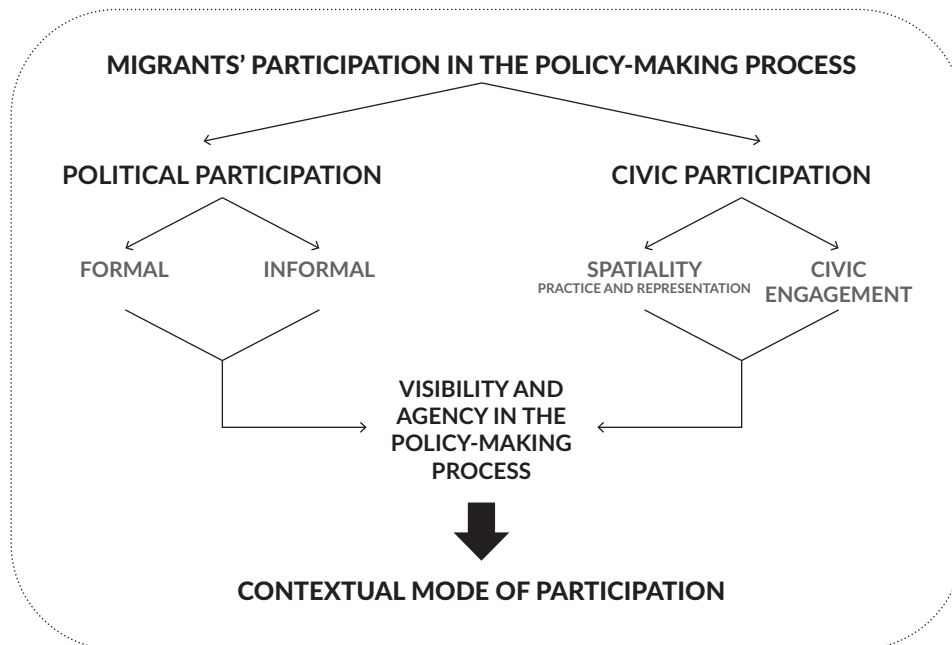
In Italy, dedicated advisory bodies—such as immigrant councils and the role of deputy councillor of foreign origin—have been experimented with since the 1990s to promote the formal political participation of foreigners at the municipal level. For instance, in the region where our case study is situated, at least 13 municipalities have established one or more advisory boards, thereby providing an official platform involving migrant associations and community representatives for the representation of foreign citizens (Menegus, 2019). However, while these processes have encouraged the formation of some migrant associations seeking representation, over time, advisory boards have shown limited capacity to represent the evolving social composition of migration and its internal diversity. Moreover, they have had little influence on local decision-making processes. Recent studies in Italy suggest that there is a trend towards the disappearance of these advisory boards in smaller municipalities (Bertazzo, 2021; Semenzin, 2022).

Moreover, as migrants and their descendants become more integrated into local society and gain Italian citizenship—and with it, political rights—participation and representation are increasingly shifting from dedicated advisory bodies to traditional democratic forums. However, the impact of these recent changes at the local level remains underexplored.

The second aspect that we highlight concerns the actual acknowledgement and involvement of migrants in community life through the use of public spaces, such as squares, public facilities, and gathering places. The fact that the ability to use and be visible in public spaces is granted and legitimised (both symbolically and practically) by the hosting local community significantly affects the migrant communities' capacity to participate in and influence policy-making. Participation in policy-making can occur both directly and indirectly. Direct participation is the involvement of migrant representatives (or other “bridging figures”) in the policy-making process, while indirect participation concerns the visibility and presence of migrants, and their ability to have their needs heard in various local contexts. This can also come about through informal activities and uses of public spaces which may indirectly influence policy-making (Verba et al., 1995). For example, using public spaces like a town square to organise events related to minority communities can enhance their visibility and recognition within the local community. This increased visibility can, in turn, lead to greater acknowledgement and give the minority group a stronger voice in the policy-making process. The concept map in Figure 1 illustrates the various dimensions of participation and their interactions.

These dynamics constitute a particularly sensitive issue, because participatory processes can sometimes be used instrumentally to neutralise conflict and pacify decision-making, without genuinely acknowledging diverse perspectives or empowering citizens (Crosta, 2003). This is especially problematic for marginalised groups, such as migrants (Beebeejaun, 2006), who often have weak voices and limited representation. When the voiceless groups are excluded, participation can become selective, exacerbating discrimination and conflict among different groups (Lefrançois, 2021), and fostering hostile environments.

Cognetti (2022) identified three theoretical frameworks based on the level of citizen engagement and the role of public actors within which to analyse participatory processes. In the first framework, the institutional actor has the leading role, promoting and constructing both the participatory process and the guidelines within which this takes place and through which citizens' agency is directed (and constrained). The second focuses



**Figure 1.** Migrants' participation in the policy-making process.

on active citizen engagement in organised, institutionally supported projects. Here, citizens are involved in interactions and social participation with respect to specific, even small-scale, policy-making and place-making projects concerning different common issues and themes. This framework is strictly context-based, and it is used to create and co-design collective spaces of identity and self-representation. The third framework regards all the actions that citizens take autonomously, without institutional guidelines and support, with the aim of transforming their social environment. These spontaneous actions position participation outside the institutional framework and highlight the importance of everyday life and practices as instruments with which to change the urban environment. While these frameworks are useful for analysis, they are not mutually exclusive, because participation is rarely entirely top-down or completely independent. Instead, a combination of these frameworks often defines the participatory process.

Thus, in an effort to underline both the role of institutional actors and the agency of citizens—especially migrants in both formal and informal settings—the following analysis will explore if, how, and to what extent migrants are able to participate in the policy-making process by being recognized and included within the local context of our case-study town. If we consider SMTs as an emerging urban scale and their main squares (or other frequently used public spaces) as sites—two overlapping and connected areas where “actors” claim to transform themselves (Isin, 2009, p. 368) through their participation in public spaces and where civic participation may occur—we can argue that understanding the changes in the meaning attributed to these public spaces by administrations is essential for grasping the extent to which migrants are “granted” space to be part of them. From this perspective, the analysis will also examine how migrants directly or indirectly influence the planning and implementation of integration and participation policies. In this regard, migrants' participation in the policy-making process can have a strong impact on the transformation of the social and urban environment at the local level, potentially improving social cohesion and laying the foundations for a more inclusive society.

To fully account for the various dimensions of participatory processes, the analysis will adopt both horizontal and vertical perspectives. This approach considers the relationships between different levels of local governance and between institutions, as well as among various actors (civil society, third sector, and institutions) at the same level. This will allow the identification of a mode of participation closely linked to the specific context of the case study which also reflects the local and small-scale dimensions of the town. This, in turn, will enable interpretation of participatory dynamics and processes at the local level in SMTs.

### 3. Methods and Context of the Analysis

This article presents the results of qualitative research conducted within the EU-funded project PISTE—Participation in Small and Medium-Sized Towns: Experiences, Exchanges, Experiments, which involved policy analysis and 17 semi-structured interviews with policy-makers and civil society actors in the case-study town, as specified in Table 1.

**Table 1.** Interviews sample.

Interviewees	Number of interviews
Mayors, councillors, and city-level officials	4
Upper-level public authorities	2
Non-profit actors and service providers	8
Migrant-run associations	3

The policy content analysis focused on the regulatory framework for migrant integration at the local level and the measures implemented by the municipality of this small town. The interviews were conducted with key actors such as mayors, councillors, and representatives from administrations with opposing political orientations that had governed the town over the past 15 years. The analysis also involved officials working in services aimed at migrants and representatives of civil society organisations, including three associations established and managed by migrants. The primary methodological goal was to ensure that all actors involved in the migration experience were adequately represented and had their voices heard.

The questions put to institutional actors focused on the relationship between territory and immigration, its evolution over time, available services, the assessment of migrants' participation in policy-making, and their visibility in public spaces, as well as the communication and monitoring of related activities. The questions put to non-institutional actors were similar but concentrated more on the perception, significance, and modes of migrants' participation in both policy-making and public spaces.

Policy documents and interviews were analysed using critical discourse analysis (Fairclough, 2003), which connects textual and contextual elements in a critical and recursive analytical movement. The material was thematically organised, and connections were identified using a thorough interpretivist perspective.

Conducting interviews on migration issues is undoubtedly a complex task, given the strong influence that political, cultural, and value-based positionality exerts on both interviewees and researchers (De Andrade, 2000), particularly when participants view integration as a one-sided endeavour that is solely the responsibility of migrants. As in other contexts, the migration debate in the case under study was highly politicised and imbued with symbolic and ideological meanings, which necessitated constant critical

reflection on how the positionality of both parties affected each stage of the research—from identifying contacts to data collection. Building trust with participants was essential to ensure that they felt comfortable expressing their difficulties and ideas, regardless of their political stance. This relation was facilitated by the researchers' growing familiarity with the area and the actors operating within it.

The case study focused on a small town in central Italy with 8,243 inhabitants, of whom about 10% were foreign residents (833 foreign residents, according to the Istituto Nazionale di Statistica, n.d.). The regional context in which the town is located also has a relatively high percentage of foreign residents—around 10.6% of the total population. Although the share of foreign residents in the town has decreased in recent years, mainly due to the acquisition of Italian citizenship by long-term foreign residents, the percentage remains higher than the national average (8.2%). This makes the town a valuable case for analysing migrants' participation.

Tables 2 and 3 summarise the characteristics of the case-study town that are most relevant to the present discussion. Table 4 provides an overview of the political shifts the town has experienced since the introduction of direct mayoral elections under Law No. 81 of 1993.

**Table 2.** Demographic variables about the migrant population at the local level.

	Migrant population	Immigration rate	Variation 2011–2021	Under-20 migrants	Female migrants
Case-study municipality	833	10.1%	–32.0%	23.1%	53.6%

Source: Andriopoulou et al. (2023).

**Table 3.** Migrant population by countries of origin at the local level.

	1st national group	2nd national group	3rd national group	4th national group	Number of countries of origin
Case-study municipality	Morocco (24.3%)	Albania (22.6%)	Romania (17.3%)	Nigeria (10.0%)	41

Source: Andriopoulou et al. (2023).

**Table 4.** List of elected mayors' political parties since 1993 and policies implemented concerning migrants.

Period	Political position	Policies implemented concerning migrants
1993–2000 (held for two consecutive terms)	PDS (the left-wing democratic party)	None.
Prefectural inspector		
2001–2006	Centre-left-oriented civic coalition	Proposal for an immigrant council (never appointed).
2006–2016 (held for two consecutive terms)	Right-oriented civic coalition	Proposals for ordinances banning gatherings and burqas in public places; adherence to a memorandum of understanding on the validity check of mixed marriages.
2016–present (held for two consecutive terms)	Centre-left-oriented civic coalition	An intercultural public event organisation (Popoli in Festa); election of a city councillor with a migration background; the establishment and recognition of a mosque and a non-Christian cemetery.

## 4. Migrants' Participation and "Visibility" as Seen by Institutions: From Hostility to Mediated Inclusion

Since the early 2000s, immigration has been among the most contentious issues in the case-study town's political debate, because the migrant population has accounted for at least 10% of the total population. In this regard, the town is an interesting case because it exhibits significant transitions in the local administration's approach to migrants' participation in local life. In recent decades, the boundaries that define the extent to which migrants can engage with the communities they live in have either expanded or contracted, depending on the political landscape. This reflects a diverse political representation, where opinions on migrants' participation often vary widely, sometimes even being in direct opposition to each other. Consequently, political alliances or rivalries have significantly affected access to resources, civic engagement, and the inclusiveness of local governance processes. This is largely because, as observed in other contexts, migration is a prominent issue on the local political agenda in the case under analysis. Both inclusive and exclusive proposals significantly shape the programmes presented to citizens.

The particular case analysed in what follows illustrates how, despite an overall atmosphere of hostility, social and political changes have significant transformative effects. They enable the emergence of key actors who, under specific conditions, can become valuable assets for migrants' participation in SMTs.

### 4.1. "Not to Suffer Migration but to Govern It": Practising Hostility Through Public Spaces

The case-study municipality had been administered for 10 years (2006–2016) by a right-wing-oriented populist political party characterised by a strong anti-migration discourse at the national level. The way in which migration-related issues were administratively handled in that period was described by a former policy-maker as follows, with an emphasis on the limited resources made available to small municipalities:

I had to deal with an ever-increasing flow of foreigners coming to [case-study municipality]....We local administrators [of small places] were left very much alone in the territory, and then there was a choice to be made: Either you suffered immigration, or you governed it....We decided to govern it [and] not to suffer it. (Int\_1)

A particular view of migrant integration—understood in terms of respect for Italian laws, culture, and local traditions—characterised the governance by the right-wing administration of local immigration, fostering hostility against migrants:

Firstly, integration means respecting the laws of the state...then it means respecting our culture and our traditions...that is to say, when I go to another person's home I respect their traditions, their culture, their roots, and all their customs....It would be right for those who come to our country to respect everything that is linked to our history. (Int\_1)

This approach to integration has also influenced the administration's relationship with the foreign communities residing in the area. On the one hand, since taking office, the administration had not implemented any measures aimed at promoting the political participation of migrants (e.g., by establishing councils or appointing deputy city councillors). Instead, it had sought to establish informal and situational

relations with key representatives, mostly in relation to security issues, as a city official explained during an interview:

As soon as we took office, I called all the representatives of the various ethnic groups...from the Imam to others, and I immediately made matters clear: If you are here to work, to commit yourselves, and not to create situations that are outside the law, you will get the maximum help from me. (Int\_2)

On the other hand, the “not-to-suffer-but-to-govern migration” period saw a series of exclusionary measures and ordinances that significantly impacted the everyday lives of migrant communities, and particularly their participation and visibility in public places, such as the ban on wearing the burqa in public. A hostile environment was concretised through the implementation of measures that created a differentiated and conditioned access to public space.

Hostile measures were especially directed at Islamic residents and black Africans. Indeed, shortly after taking office, the administration denied authorization for an event previously held annually in the town—the annual gathering of Islamic communities and associations based in the province—and pushed for the abolition of pork-free meals for Muslim children in public schools. Additionally, the right-wing coalition approved ordinances banning gatherings and burqas in public places, and it signed a memorandum of understanding between the municipality and the police headquarters to check civil marriages between Italian citizens and foreigners for evidence of marriage fraud. Recalling how local policies may become a battleground where different levels of governance conflict over exclusive measures approved by local authorities (Ambrosini, 2013), the burqa ordinance was contested by the prefecture and made ineffective. However, this ordinance was still enforced at the local level by instructing municipal police to conduct regular security checks whenever a woman wearing a burqa was seen in a public place. Another proposed ordinance prohibited the assembly of migrants, particularly from North Africa, in public spaces.

The right of migrants to be visible in public space should meet certain standards of integration and behaviour that are pre-conditions for inclusion, as is clear from the following statement by a former policy-maker:

Migrants are perfectly fine with us, but they must comply with our protocols. (Int\_1)

As can be seen, according to this policy-management approach, migrants’ civic participation and their visibility in public spaces are “permitted” only if the migrants are recognized by the administration’s parameters as “good” and worthy of residence, similarly to what is reported by Hackl (2022, p. 991). In this context, within a discourse of alterity that emphasises the difference between native citizens and migrants, differential participation and access to public resources is advocated. The dominant position of the receiving country is invoked also by means of the analogy between homeland and home, as highlighted by a former policy-maker:

I have to respect my culture, my tradition. You cannot come to my home and tell me you do not eat pork....If today there is pork there is pork, [if you do not want it, then] only eat vegetables....Eh sorry, this is my tradition. (Int\_1)

You cannot come here and somehow mock or offend or be highly critical of our traditions, which are often religious, cultural, historical. (Int\_1)



#### 4.2. “The Main Square Is a Meeting Place”: A Renovated Access to Public Spaces

In 2016, the municipal administration changed, and a mayor from a centre-left-oriented civic coalition was elected. The change in the local government led to a shift in the boundaries between exclusion and inclusion, as well as in the perception of migrants’ participation in local life. However, it is important to note that, although left-wing governments may generally adopt more inclusive measures in the context under analysis, they did not always implement the most inclusive policies toward migrants, often due to varying preferences within their constituencies (Harris & Römer, 2023). At the same time, the migrant presence itself in the area had been shaped by significant transformations, such as the gradual advent, stabilisation, and naturalisation of new generations in the public sphere, which had affected the conception and forms of representation and participation of migrants and their descendants. For example, advisory boards were now considered outdated by the centre-left administration, because the participation of migrants should take place within the framework of public life as a whole and not be relegated to immigration issues alone:

We didn’t want it [the migrants’ council]. I think it’s a segregating thing. It was fine in the 1990s, but in 2022 it’s not a thing to do....[Migrants] have to participate in the democratic life of a country as a whole...for instance we have neighbourhood councils, the youth council, which is a group of young people ranging from 18 to 35 years old, or local associations in which migrants are involved. (Int\_2)

As corroborated also by the results of policy analysis, in this current policy approach, visibility and participation in public spaces such as the central city square, parks, and other areas shared with the local population were also important indicators of integration:

When you go to the square, which is the main meeting place, you do not see those separate little groups anymore, but people talking freely among themselves. So there are no more divisions. (Int\_2)

The emphasis on non-ethnic aggregation in public spaces indicates both the bottom-up agency of migrants and the support of local authorities for such participation. Participation is a multi-layered process and occurs in the interaction between top-down nation-state efforts and bottom-up citizen acts of redefining such efforts (Horst et al., 2020). In this regard, in the shift in attitudes towards migrant participation in the small town considered, visibility assumed political significance (Brighenti, 2010), and it had been regularised by a number of specific initiatives and policies which, in their implementation, took account of migrant participation, even if in a fragmented manner. A public multicultural event, funded by the municipality since 2017, whose purpose was to foster integration between cultures, was one of the few occasions of formal exchange and encounter between migrant associations and the local administration. Over the two days dedicated to the event, citizens with migrant backgrounds had the opportunity to exhibit their culture of origin through music, dance, and food in the main square. As explained by a city official during an interview, the festival was jointly organised by the municipality and resident migrant communities:

Meetings [with the municipality] take place through individual or group interviews, when we explain what’s new, how, listen to their availability, their proposals, and anything else they can say and do [as far as organisation is concerned]. (Int\_4)

As well as being one of the few bridges to institutions, this event also had a symbolic function (Oomen, 2019) because it was intended to strengthen the legitimacy of the residents' identities through visibility in public spaces, while reproducing traditions from their home countries.

## 5. Policy Participation Through Institutionalised Mediators: From Boundary-Spanner Agency to Person Dependency?

Apart from this multicultural event, the relationships between migrant communities and local policy-makers had generally remained informal, relying heavily on the mediation of a few key figures. These included individuals such as the local Imam, a woman of foreign origin working at the local immigration office (managed jointly by the municipality and the local social authority), and members of voluntary associations, some of whom might also hold overlapping roles within the municipal administration (Semprebon et al., 2022).

For example, the immigration office employee was also one of the founders of the Albanian association, while the president of another voluntary association had previously been a member of the municipal council. These overlaps contributed to blurring the boundary between public administration and local foreign residents, facilitating the transmission of specific requests and needs to the municipal administration through informal channels.

In 2016, a major turning point in the “formalisation” of such figures was the election of a municipal councillor with a migration background, who was responsible for social inclusion and European policies within the centre-left administration. A municipal councillor is a public official who represents the citizens of the municipality where he or she has been elected and has a guiding role (in the case of majority councillors) and a supervisory role (in the case of opposition councillors) with respect to the municipal administration. The election of such a councillor in the case-study town represented a major shift in the political participation and representation of migrants, as well as in the configuration of the local migration policy-making process and its outcomes. After 10 years of right-wing governance marked by hostility towards migrants, the councillor's campaign focused on raising awareness about issues such as headscarves, religious rituals, and places of worship. This was achieved by means of educational initiatives in schools and public spaces, as well as interfaith meetings with the Catholic Church.

During the centre-left administration, the councillor was essential for creating a bridge between local public administration and migrants amid an asymmetry of resources and relational skills. This boundary-spanning agency (Ahmed, 2020) enacted by “a person who would be the community's voice to the administration” (Int\_3) helped to build and maintain networks between institutions and migrant community members. City officials, in fact, as explained during interviews, recognized the councillor's prominent role:

Undoubtedly, having a person of foreign origin [a young man of Moroccan origin] in the council helps. You can see the change because nowadays if there is a problem, they [institutional actors] call you [Moroccan origin councillor]...they turn to me or directly to the mayor...this can already be considered a form of interest and participation that until a few years ago did not exist. (Int\_3)

Thanks to the municipal councillor, I have a privileged channel that allows me to reach much deeper [into the needs of migrant communities] than perhaps other people can [who lack this link to local authorities]. (Int\_2)

Moreover, the councillor seemed to have an essential role in overcoming the hostility that migrant communities had experienced for so long, making them feel listened to and considered, as expressed by migrants' representatives during interviews:

We have needs, and how do we meet these needs? Well, we've recently figured it out. We realised this when [name of councillor] became a councillor, because now we [the Islamic community] have access to topics and discussions in arenas we couldn't reach before. So, this is important, having someone involved in these issues, having them in strategic positions....It makes a difference. (Int\_5)

[The councillor] is a great person, I have always supported him, and he has always supported us, along with the municipality of [name of the town], over the past four or five years. They put us in the spotlight [by creating the multicultural event Popoli in Festa] even against the will of the locals, so to speak. It's not easy... (Int\_6)

At the same time, this councillor acted not only as a boundary spanner (bringing migrants closer to the municipal administration) but also as a sort of migration-policy entrepreneur, seizing "windows of opportunity" to promote policy change (Kingdon, 1995). Policy entrepreneurs are usually identified as individuals who operate as advocates of policy change by putting forward convincing arguments on how to define and address a problem; by developing policy networks and coalitions; and by promoting pilot projects and eventually finding resources to support certain measures and drive policy change (Mintrom & Norman, 2009). While in other SMTs in Italy some migration-policy entrepreneurs have been identified among mayors and members of civil society organisations (Semprebon et al., 2022), the case analysed reveals the rise of such figures among municipal councillors of foreign origin as well.

Recalling such migration-policy entrepreneurs, in 2019 the councillor in the case-study town was among the architects of the Charter of Mayors on Social Inclusion in the Euro-Mediterranean Area, which was promoted by two main municipalities in collaboration with 24 others primarily located in the Marche Region. The purpose of the Charter was to provide a shared framework for social inclusion policies at the local level. In strong opposition to the vision of the previous right-wing administration, it placed great emphasis on recognizing diversity and ensuring the right to worship of religious minorities.

In the case-study town, the Charter had been implemented, for example, by helping the Albanian and Islamic associations to hold Arabic and Albanian language courses (providing a space and some teaching materials). More importantly, following the principles of the Charter, the councillor's role was also crucial for the recognition of the local mosque as a place of worship by the municipality in 2020, mediating between the Islamic community and public authorities. The case-study municipality is today the only place provincially (and the fifth nationally) where there is a mosque recognized as such. Furthermore, by leveraging networks and relationships built outside the municipal context, e.g., in academia, the councillor played an important role in the municipality's access to European funds through an Asylum, Migration and Integration Fund project fostering new interactions among local administrations, local associations, and supra-local actors.

The presence of the councillor and the receptivity of the local administration also stimulated the resident foreign communities to advance their grassroots claims through their representatives:

Now things are different, and we feel encouraged....Let me give you an example: We wanted a cemetery and didn't know how to go about it, but now we have one....And how was this achieved? It was thanks to [the councillor] being there, knowing how things work and who to talk to. (Int\_5)

In this respect, specific structural necessities also help concretize responses to various needs such as an Islamic cemetery for Muslim Covid-19 victims. However, the fact that, once the request for an Islamic (or non-Christian) cemetery reached the municipal council, it passed unanimously, was the result of a campaign to “normalise” the participation and visibility of migrants in the social context. It should be pointed out, however, that while on the one hand Covid-19 expedited the creation of some specific services and spaces aimed at migrants through a direct relationship with public authorities and communities, on the other hand it slowed down, or in some cases suspended, the existing relationship by delegating public services to third-sector representatives and/or voluntary organisations mainly because of the first lockdown restrictions.

As the aforementioned example confirms, having a migrant representative as a “gatekeeper” within the local authority undoubtedly facilitates greater participation and visibility in public spaces, as well as in decision-making processes. Both specific needs—such as the establishment of an Islamic cemetery for Covid-19 victims—and broader aspects, such as the increased visibility of diversity in public spaces, are addressed through the involvement of these representatives. However, biases may influence decision-making: For instance, the gatekeepers may feel compelled to respond to every request made by the community. If they are unable to engage in effective gatekeeping, they risk exclusion from their own community and may be perceived as incapable of navigating interactions with authorities or as having lost their cultural identity.

Lastly, it should also be noted that these highly personalised interactions may also become counterproductive because the relationship between the parties can turn into a “certain-person dependency” characterised by subordination to person-specific linkages. In such cases, another challenge may be an ethnically segregated (Bonizzoni & Marzorati, 2015) mediation in policy discourse and practice, and the lack of participation in policy implementation of migrants not represented by associations and/or those from other communities.

## **6. Conclusions: Facing Hostility in Small Towns Through a Place-Based and Personalised Mode of Participation**

In the previous sections, we outlined the dynamics of political and civic participation involving migrants within the local context of the small town at the centre of our analysis. In that town, specific social and political conditions had given rise to a distinct form of hostility manifested through both direct and indirect denial of migrant communities' access to public spaces and a failure to address their specific needs.

First, we have demonstrated that, even in such a small community, migration-related issues have significantly influenced the policy agenda for at least the last 20 years, making the political and civic participation of foreign residents a significant issue for both right-wing and centre-left ruling coalitions. We have observed how the alternation of these two political factions in governing the city coincided with a notable shift in the understanding of socio-spatial relations between migrants and natives and how these spaces were inhabited. The result was a gradual improvement in the space and acknowledgement granted to migrant residents and their participation in social and political life.

Most importantly, we have highlighted that, in such a small and localised context, the presence of an intermediary figure able to act as a bridge between migrant groups and institutions proved to be a key factor in facilitating the effective participation (mediated or not) of foreign residents and in overcoming the atmosphere of (experienced and perceived) hostility.

Numerous scholars (Haselbacher & Segarra, 2021; Marzorati et al., 2017) have underscored the delicate role played by local policy-makers, particularly mayors. They have noted that their proximity to the population in SMTs positions them as intermediaries among the various demands they encounter. In regard to the (official or unofficial) representatives of migrants, this intermediary role becomes even more essential in bringing migrants' perspectives onto the policy agenda and shaping the transition from hostility to engagement and participation.

In relation to active political participation, we have referenced Ahmed's (2020) concept of boundary-spanning agency and the figure of the migration-policy entrepreneur (Mintrom & Norman, 2009) to highlight the importance and role of these actors. In doing so, we have emphasised that, in SMTs, where the presence of such actors is often limited to a single individual and typically characterised by highly personal or even intimate relationships with migrant groups, this role can become a double-edged sword, because it ties participation to dependency on only one person.

Given this, what elements of migrants' participation within the context analysed can we assume to be specifically linked to the small size of the town and the local dimension investigated? Can these elements be summarised in a local "mode" of participation that provides a conceptual framework within which to understand participation in SMTs, particularly those characterised by hostile local policies?

The analysis seems to identify a place-based and personalised mode of participation characterised by the following features.

The first feature is the importance of the town's spatiality, particularly the presence of public meeting places shared by migrants and natives. The small size of the town and the limited dispersion of focal points have played a significant role in both hostile and inclusive periods and in shaping attitudes that give different meanings to those spaces. During the hostile period, forced coexistence in shared places limited ghettoization and exclusion, but it also compelled the administration to pragmatically address issues related to the public acknowledgement of foreign residents. Hostility towards migrants during that period was manifested through ordinances prohibiting gatherings, restricting the use of public spaces, and limiting cultural expression in schools, squares, and streets of the small town. In contrast, the more welcoming period allowed these meeting places in order to facilitate familiarisation with different people and cultures by providing space for the acknowledgement and participation of migrants. Thus, the acknowledgement of migrants in public spaces (such as festivals in the public square) and the public recognition of migrants' spaces (including the mosque and the Islamic cemetery) were perceived by policy-makers and migrants themselves as crucial in the transition from a hostile and exclusionary atmosphere to one more open to inclusion, cooperation, and engagement.

The second feature pertains to the dependency of participation on the personal and intimate dimensions of relationships. These are linked to the small size of the town, which renders participation fragile, discretionary,

and eventually fragmented. The significant improvement in participation experienced by foreign residents over the past decade—which has been attributed to the boundary-spanning agency of the second-generation councillor elected in the latest administrative elections—highlights the fragility of these achievements and the fragmented and discretionary nature of participation. The personalised nature of this representation risks generating further civic stratification (Joppke, 2007; Morris, 2003) among different groups of residents, and it could dissipate once the presence of that specific individual in that particular position is no longer guaranteed. Different levels of access to these informal forms of representation, intertwined with the small size of the town, which exacerbate community dynamics of social control, may create pockets of isolation disguised as disinterest. Another risk is tokenism, where time-based representation and participation may lose their strength and potential over time. In this context, it is crucial to consider the small size of towns, and the absence of the material and immaterial resources typically associated with larger cities, because these factors are vital for sustaining social, cultural, and political dynamics.

However, the bridging role played by the aforementioned councillor is an important factor to consider, and its positive impact on migrants' participation should not be underestimated. Indeed, despite the negative implications, the relational dimension and intermediary position of a policy-maker of this kind are assets. They enhance the relational resources of migrant residents and provide them with a vital space in which to claim their stances, thus influencing the policy-making process directly or indirectly. Furthermore, the ability of this figure to seize windows of opportunity and to develop strong networks and coalitions can lay the bases for further improvements in migrant participation levels. This also extends to the inspirational impact that such an actor can have on the second- and third- generation migrants, among whom we may find future representatives of fluid and transnational identities—agents of what has been termed “intimate globalisation.”

In conclusion, to better leverage the characteristics of small towns where potential “relational power” can be cultivated, it is essential to strengthen and stabilise the roles of the above-described figures within institutions. To counteract dependency on the personal and intimate dimensions of relationships and to avoid highly selective representation, it is important to promote the expansion of inclusive political-administrative spaces. Special attention should be paid to those “new” citizens who can assume this culture-bridging role, such as representatives of the second-generation migrants. In a context where migration has been present for decades, analysing the civic and political participation of the second-generation migrants and new citizens is crucial.

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## About the Authors



**Alba Angelucci** (1988) is a researcher in sociology at the Università degli Studi del Piemonte Orientale, where she lectures on urban sociology and the sociology of migration. Her research interests include migration and territorial welfare, which she analyses from an interdisciplinary and intersectional perspective. In particular, her recent research subjects include the following: migrants' participation and inclusion in small and medium towns from a European perspective; social services for migrant populations at the local and regional level; gendered and intersectional urban citizenship; and territorial welfare policies.



**Gül Ince-Beqo** (1984) received her co-tutelle PhD at the Catholic University of Milan and Regent's University London. Her research explores the intersection of migration, family, religion, education, and policy-making. Currently, she is a post-doctoral fellow at the Department of Social and Political Sciences of the University of Milan.



**Fabio De Blasis** (1986) holds a PhD in global and international studies from the University of Bologna (2018) and he is a post-doctoral fellow at the Department of Social and Political Sciences of the University of Milan. His research interests concern several migration-related issues, including migration control policies at global, national, and local levels, labour migration, migrants' legal status trajectories, and the role of migration infrastructures and intermediaries.

# Self-Managed Housing in Vienna: Managing Ambivalences Between “Inevitability” and Resistance

Andrea Schikowitz 

Department of Science and Technology Studies, University of Vienna, Austria

**Correspondence:** Andrea Schikowitz ([andrea.schikowitz@univie.ac.at](mailto:andrea.schikowitz@univie.ac.at))

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## Abstract

This contribution addresses how self-managed collaborative housing (CoHo) groups engage in and with urban planning in Vienna and thereby how they manage the ambivalence of simultaneously getting involved in established planning and maintaining their alternative and subversive character. These groups aim to shape their own living environments and contribute to more sustainable, affordable, and collaborative housing and living. The relations and interactions between self-managed housing projects and municipal planning actors are ambivalent and include both invited and uninvited forms of engagement. To be able to realise their projects and to intervene in urban planning, CoHo groups thus need to manage the boundary between making their aims compatible with *and* challenging urban planning visions and strategies. I analyse this by paying attention to how CoHo actors enact “inevitability” while maintaining their resistance against certain urban policies. For doing so, I draw on and contribute to literature at the intersection of urban planning and STS that address public participation in collaborations and controversy contexts. The empirical materials stem from a multi-sited ethnography, comprising interviews with members and proponents of CoHo groups, observations of public and semi-public events of, with, and about CoHo, as well as documents and social media posts. I find that CoHo creates inevitability by negotiating and working on three aspects that are directly or indirectly challenged by municipal and professional actors: their relevance, expertise, and reliability. They do so by engaging in infrastructuring activities that stabilise both the inevitability and resistance of CoHo in Vienna.

## Keywords

collaborative housing; hostility; infrastructure; public participation; representation; urban planning

## 1. Participation in Urban Planning Between Hostility and Embracement

Involving different public, civic, and private actors in shaping urban spaces materially and socially is now widely regarded as both a matter of justice and as key to better planning (Allmendinger, 2001). While public authorities and planners largely welcome and, in fact, invite public participation in planning for introducing new ideas and more immediate access to public needs, they also seek to demarcate, control, and diminish public involvement in specific ways in line with broader planning strategies (Kornberger, 2012). As outlined in the introduction to this thematic issue, in practice, participation is often limited to specific well-framed questions, rather than allowing for the articulation of issues by the participants (cf. Chilvers & Kearnes, 2020; Felt & Fochler, 2010). Participation in urban planning can thus be considered as a case where public participation in shaping matters of collective concern is met with mostly indirect hostilities. This means that even if participation is generally regarded as desirable, established governance logics and entrenched ways of sensemaking in fact limit how participation can be realised in practice. I thus explore how actors who aim to participate in urban planning encounter and navigate hostility by enacting what I call “incompatibility” (i.e., compatibility with the authorities’ expectations of who is suited to be invited to participate) while resisting the pre-framed agendas and upholding alternative issues and values.

The involvement of self-organised collaborative housing (CoHo) in public housing policies in Vienna is a case in point: On the one hand, as it is stated in the current city development plan STEP 2025, “the City of Vienna invites new actors into urban development, who can realise diverse uses. Self-organisation and civil-society engagement are welcome additions of established structures” (Stadt Wien, 2014, p. 11). On the other hand, the established governance logics, planning practices, and administrative and legal regulations of the City of Vienna set indirect boundaries against more autonomous and active involvement of citizens and activists in urban planning and housing strategies (Novy et al., 2001; Sepehr & Felt, 2023), and the realisation of CoHo projects remains dependent on the explicit support and invitation by the municipality. In Vienna, access to building plots for subsidised housing constitutes a major challenge for CoHo. Land owned by the City of Vienna is mainly distributed via so-called builder competitions, where proposals are selected by a jury based on architecture, economy, ecology, and social sustainability. While the latter offers CoHo opportunities in these competitions, succeeding vis-à-vis professional housing projects remains a challenge. Competitions exclusively for CoHo projects remain few.

While the City of Vienna overall appears as a welcoming environment for CoHo (especially in international comparison), the case demonstrates the more subtle mechanisms in which indirect hostilities co-develop with specific forms and practices of participation that attune to, navigate, and negotiate the ambivalent environment in which they are embedded. Notably, “the City” cannot be regarded as a homogeneous entity that acts in completely coherent ways. Rather, different actors and units are involved in the governance of the city, and it differs how these actors relate to and address citizen participation. Against this background, this contribution analyses the case of CoHo in Vienna (so-called *Baugruppen*) and how its proponents negotiate its entanglement in urban planning in cooperative as well as conflicting ways.

To analyse these complex and ambiguous relations, I draw on sensitizing concepts and approaches from STS (Science and Technology Studies), planning and design studies that address cooperation without consensus, and the formation of publics and issues. This article contributes to these debates by developing an empirically grounded framework for analysing incompatibility, specifically CoHo’s compatibility with and

resistance to the public authorities' expectations, and CoHo's engagement with infrastructure in ways that accommodate ambivalences between hostility and openness.

In the following, I first discuss literature that deals with participation in collaboration and controversy. I then introduce the case and my analytical strategy. Next, I present my findings, focusing on three aspects which are negotiated and navigated by the housing groups for creating inevitability, namely relevance, expertise, and trust, and elaborating how this contributes to participation infrastructures. In conclusion, I discuss how infrastructuring participation might impact participation in urban planning.

## 2. Collaboration, Controversy, and Beyond: Literature and Sensitising Concepts

To analyse how housing groups negotiate and navigate invited and uninvited forms of participation, I draw on literature from STS and urban planning that deals with how actors gain credibility to promote their claims and issues (or fail to do so) in cooperative and controversy settings.

Literature on *invited* forms of public participation in research and in planning critically reflects on power relations and epistemic hierarchies in such settings that often hinder a more substantial involvement of publics. STS literature (Granjou & Arpin, 2015; Hackett, 2005; Lengwiler, 2008), for instance, addresses the issue of aligning heterogeneous cultures and knowledge practices, the tensions involved, and its (unintended) effects (Felt et al., 2016; Schikowitz, 2020; Schikowitz et al., 2023). It points to the power relations that are entrenched in the practices and routines of participatory processes that often reinforce hegemonic knowledge hierarchies between scientists and lay people, between Global North and Global South researchers, and among Indigenous knowledge systems (Chilisa, 2017; Latulippe & Klenk, 2020), which often makes knowledge integration an "exclusionary" (Klenk & Meehan, 2015) and extractivist (Latulippe & Klenk, 2020) practice. Similarly, urban planning literature, mostly from a Foucauldian tradition, has criticized ideas of "collaborative planning" (Healey, 2003) based on a Habermasian ideal of rational discourse and consensus as neglecting existing power relations and exclusions in participatory settings (Brand & Gaffikin, 2007; Flyvbjerg & Richardson, 2002; Metzger, 2011, 2013). This critique often goes along with a call for "agonistic planning" (cf. Mouffe, 1999) or "hybrid forums" (cf. Farías, 2016; McFarlane, 2011) based on productive dissent and ongoing political negotiation.

Alongside STS and planning literature on invited participatory settings and their pitfalls, studies that focus on *controversies* ask how citizens and social movements succeeded or failed when they tried to make their concerns heard. STS studies on public controversies (foremost about the regulation of environmental and health issues) have analysed how citizens and social movements have challenged dominant knowledge regimes (e.g., Anglin, 1997; Callon & Rabeharisoa, 2008; Epstein, 1996; Frickel et al., 2010; Kleinman & Suryanarayanan, 2012; Martin & Richards, 1995). These studies analyse how the actors gain or lose credibility within the dynamics of a controversy. Especially Epstein's (1996) seminal study on the role of activists in the development and regulation of AIDS treatments pays attention to how the activists both challenged and contributed to medical research, and it particularly investigates the mechanisms and strategies of the activists for being accepted as relevant and credible stakeholders that are "invited to the table." Benjamin (2013), analysing the controversy around the California stem cell initiative, attends to issues of social justice and critically reflects on the privileged position of powerful patient organisations that might reinforce existing inequalities.

Literature at the intersection of STS and urban studies on knowledge and learning within urban movements (Blok & Meilvang, 2015; De Souza, 2006; McFarlane, 2011, 2012) addresses the tensions when activists get involved in urban governance. These studies focus on how movements develop and express their concerns in ways that are recognisable to the members of the movement as well as to officials and policy actors (McFarlane, 2011, 2012), and what the intended and unintended effects are. Levine (2016) discusses how nonprofit community-based organisations gained the position of nonelected neighbourhood representatives in an urban development project in Boston, USA, and thereby superseded elected politicians. From an STS perspective, Bijker and Bijsterveld (2000) analyse how a self-appointed committee that aimed to include women's needs in the planning of public housing in the Netherlands made planners listen to them. In fact, they could make themselves heard and gain influence on planning but had to balance that carefully by not making explicit political claims and by performing a relatively narrow white, middle-class, and heteronormative conception of women-friendly planning.

Related to in- and exclusions in invited and uninvited participation, the question of representation of democratic publics has been problematised. Summarising relational conceptions of public participation from STS, Chilvers and Kearnes (2020, p. 350) emphasise:

Far from being external pre-given categories, the subjects (publics), objects (issues), and models (political ontologies) of participation are actively co-constructed through the performance of collective participatory practices, both shaping and being shaped by wider social, political, and technoscientific orders.

In this sense, the question concerning public participation is not how to best represent a pre-given public, but how publics are co-constituted in specific participation formats, together with the issues that are at stake (Marres, 2007). At the intersection of STS and urban studies, scholars like Metzger (2013) and Kornberger (2012) make a similar argument for the involvement of “stakeholders” in urban planning and governance. Criticising the conception of the planner in collaborative planning as a mediator who would select relevant stakeholders and bring them together in planning processes, Metzger (2013) argues that rather “stakeholderness” is actively constructed to include certain actors and issues, and exclude others (for similar arguments from a Foucauldian perspective concerning “citizens” as political subjects see, for instance, Cruikshank, 1999). While these studies implicitly frame the publics that are involved as passive entities that are enrolled by overly powerful planners (cf. De Laet & Mol, 2000), Felt and Fochler (2010) attend to how the participants in different participation formats constitute themselves in relation and demarcation to other publics. This already hints at the ambivalences and subtle entanglements between invited and uninvited participation that are at the core of this article.

I aim to make sense of the entanglements of mutual mobilization, cooperation, and competition, and how CoHo manages these ambivalences to simultaneously make themselves invited yet maintain their subversive and alternative stance. I draw on sensitising concepts that highlight infrastructures and spaces that allow for cooperation without assuming consensus (Dagiral & Peerbaye, 2016; Guston, 2001; LeDantec & DiSalvo, 2013; Slota & Bowker, 2017). The notion of “infrastructuring” focuses on bottom-up practices for facilitating cooperation between different actors (Dagiral & Peerbaye, 2016; Fariás, 2016) that goes along with the formation of publics and issues. For example, literature from critical migration studies (Kapsali, 2020; Wajsberg & Schapendonk, 2021) has analysed the informal and alternative infrastructuring activities of

people on the move which complement, subvert, and challenge formal policies and dominant infrastructures for managing migration, while relating to the formal infrastructures in various ways. STS-inspired design studies (Bjögvinsson et al., 2012; LeDantec & DiSalvo, 2013) emphasise that engagement in designing urban spaces can contribute to “infrastructuring publics” by providing opportunities to meet and exchange knowledge and experiences from which common issues can form. To analyse how “cooperation without consensus” between different political, administrative, and professional actors can take place, Star and Griesemer (1989) introduce the concept of “boundary objects” (such as forms, standards, or concepts) that mediate between actors but hold different meanings for each of them.

This study aims to contribute to these literatures by paying attention to the entanglement of cooperation and controversy, the mutual mobilisation of the actors involved in a specific cultural context, and the possible (unintended) effects of managing the ambivalences between them.

### 3. Materials and Analytical Strategy

I now introduce my empirical case and materials, as well as how I analysed these materials based on my sensitizing concepts. The analysis is embedded in a multi-sited ethnography around CoHo in Vienna which I conducted in varying intensities between 2018 and 2023.

Most CoHo projects are initiated out of a dissatisfaction with the private housing market as well as the public housing provision (Rogojanu, 2019; Rumpfhuber et al., 2012; Schikowitz & Pohler, 2024). The groups simultaneously challenge and contribute to the governance of housing. CoHo groups and organisations—no matter what their exact aims might be—are involved in shaping matters of collective concern. The City of Vienna invites and restricts their involvement in mostly indirect ways, and the CoHo groups (need to) make themselves compatible with the public authorities’ aims and thereby *invitable* in the first place, *yet also* resist these aims to be able to realise different kinds of housing and living (cf. Schikowitz & Pohler, 2024). This case lends itself to the analysis of invited and uninvited participation, and of the co-construction of (indirect) hostilities and participation practices. The various actors are in conflict and competition, yet they simultaneously cooperate and learn from each other, and they try to mobilise each other for their respective targets.

CoHo in Vienna comprises a range of projects with diverse aims (Czischke et al., 2020; Lang & Stoeger, 2018), such as more affordable, sustainable, and communal housing, a de-commodification of housing, or an adaptation of housing options for specific needs, such as aging, new forms of work, different household—and family forms, etc. Many projects want to change not only their own housing situation but also the housing system and urban governance more generally. What they have in common is that a group of future dwellers joins forces and acts as a developer who commissions and engages in the planning, construction, and management of their own building. In addition, there are individuals and organisations who aim to foster CoHo, like associations or umbrella organisations that encompass several projects.

In a multi-sited ethnography (Falzon, 2009; Marcus, 1995), I accompanied CoHo groups to different (mostly public and semi-public) sites and formats where they exchange and communicate amongst each other and with different other actors involved in urban planning, such as municipal policymakers and politicians, urban studies scholars, civil society initiatives, professionals and journalists. I focus here mainly on observation



protocols from about 20 public and semi-public events, talks, and meetings (online and in presence), 8 formal interviews which I conducted with members of different CoHo groups and organisations, as well as documents and social media appearances, following Pink et al. (2016). The direct quotes in the findings are from interviews (*int\_number*) and from observations of events (*event\_number*), which I translated from the original German. They respectively stand for many similar statements in my materials. To protect the anonymity of my informants, I do not provide unnecessary details when quoting them.

While the observations of events also include utterances of members of the City of Vienna and other actors, my analysis for this article focuses on the perspective of the CoHo members and proponents. Thus, when I refer to the hostilities that these actors encounter, this reflects their experience of hostilities, rather than providing factual statements or my analytical findings about the stance of the City of Vienna. Likewise, I do not judge if the concerns of and about CoHo are justified or not.

The analysis of these materials is interpretive, based on open and focused coding, and accompanied by mapping relations between actors. These methods facilitated theoretical sampling and generated observations and ideas for further analysis (Charmaz, 2006; Clarke, 2005). In particular, the mapping directed my attention to the fact that the diverse actors—both individual persons and organisations—were entangled in various ways and that these actors assemble and re-assemble in various constellations at different events, projects, and initiatives. This observation that there were no clearly delineated sides through which the actors could be separated, sparked my interest in the entanglement of invited and uninvited forms of engagement in the first place and guided further focused coding and analysis (Charmaz, 2006).

The analysis is mainly based on the concepts of “invisibility” and “infrastructuring.” When analysing how CoHo enacts what I call invisibility, I paid attention to how they anticipate and experience the public authorities’ (implicit and explicit) expectations about what would make them eligible to be invited to participate, and how they seek to meet these expectations (cf. Epstein, 1996). Thus, in a first step, I analysed what hostilities the CoHo proponents experienced, and how they saw overcoming these hostilities as necessary to become invited to participate. In a second step, I analysed which strategies the CoHo proponents applied to actually overcome the hostilities and to create compatibility with the public authorities’ expectations, both in ad hoc and more stable ways. I found that while seeking compatibility, CoHo proponents simultaneously tried to uphold their own autonomy and their critical stance that might contradict the authorities’ expectations.

To make sense of this entanglement of mutual mobilization, cooperation, and competition, and how CoHo manages the ambivalences involved, in a third step I analysed CoHo’s infrastructuring activities (Bjögvinsson et al., 2012; LeDantec & DiSalvo, 2013). Infrastructuring goes beyond ad-hoc strategies to allow for invisibility, by creating more stable structures (Slota & Bowker, 2017) that grant CoHo eligibility to participate in urban planning and housing. Simultaneously, infrastructuring provides CoHo with opportunities to stabilise not only their fit with the authorities’ expectations, but also possibilities to resist and counter-act the City’s housing policies and to realise alternative ways of housing and living. I thus analysed CoHo’s infrastructuring activities (building on the heuristic by Schikowitz et al., 2023) that stabilise both invisibility and resistance. I paid attention to how they build material structures and spaces that allow for the formation of publics and issues (cf. Bjögvinsson et al., 2012; LeDantec & DiSalvo, 2013); organisational structures, legal models and standards (cf. Slota & Bowker, 2017; Star & Griesemer, 1989) that anchor CoHo in administrative and legal frameworks, as well as shared narratives and arguments

(cf. Felt, 2017; Sepehr & Felt, 2023) that legitimise and normalise the involvement of CoHo in urban planning strategies.

Yet, infrastructuring cannot be done by the housing groups alone. They need to mobilise the City of Vienna and other actors, which in turn try to stabilise their own agendas and likewise enrol CoHo for their ends. Infrastructuring thus coproduces specific forms of participation with forms of co-option *and* subversion.

## 4. Findings: Creating Inevitability

In the following, I present how the housing groups encounter and address hostilities, mainly by political and administrative actors, but also by professionals like building contractors or construction companies. This concerns how CoHo proponents perceive hostilities and how they act according to this perception.

I find that the groups navigate and negotiate mainly three interrelated hostilities to constitute and manage their inevitability into urban planning processes that concern (a) relevance and representation, (b) expertise, and (c) trust and reliability. In a final section, I revisit these findings and elaborate on how CoHo proponents engage in infrastructuring to stabilise both their inevitability and their resistance.

### 4.1. Negotiating Relevance and Representation

CoHo proponents perceived it as hostile that, in their view, some representatives of the City of Vienna discredited the relevance of CoHo for broader urban populations and their needs, and simultaneously posted excessive demands and expectations of what CoHo should achieve for their neighbourhoods. In the following, I reflect on how housing groups react to these hostilities by stressing their own relevance, yet distancing themselves from excessive demands and co-option for goals that they do not share.

Overall, the accusation concerning the low accessibility of CoHo by broader populations is perceived as unfair, and CoHo proponents relate it to the City's hostility, as one of my interviewees points out:

The City is, I would say, supportive only to a very limited extent towards us *Baugruppen*....And because of this [lack of support], our projects are accessible to others only to a limited extent. So you need a lot of skills, know-how or be willing to acquire that, to have this access and to get to the next step, so that it is also possible for broader layers of the population. (int\_4)

Related to this, the housing groups see themselves confronted by what they frequently refer to as “the bobo accusation” (event\_6). The term “bobo” (the short form of *bourgeois bohémien*) is used for the inhabitants of certain “hip” city quarters (such as Berlin Kreuzberg or Neubau in Vienna), who are often well-educated, economically well-off, and adopt elements of a DIY and counter-cultural aesthetics and lifestyle. In the alleged view of City representatives, CoHo proponents would adopt a bottom-up rhetoric and aesthetics, while actually furthering their own interests or even contributing to gentrification processes. They are addressed as belonging to an already privileged group that is far removed from the needs and problems of the working class which is still seen as the primary addressee of Viennese social democratic politics. These concerns are perceived as dismissive, as they run counter to the self-understanding of most CoHo proponents and they mostly counter this accusation vehemently. They emphasise that they are, instead,

engaged citizens who devote energy and spare time to contributing to the public good, using their privileges for, rather than against, those who do not have the resources to engage in bottom-up projects. To demonstrate the relevance of CoHo for broader populations, the housing groups foreground the concrete benefits they create for whole neighbourhoods, fulfilling the City's expectations. These social achievements, such as kindergartens, event spaces, or refugee apartments, correspond well with the housing groups' common values and aims. Yet, the housing groups often perceive the expectations as too high, pointing out:

[CoHo] almost got abused for invigorating a neighbourhood or so, with many requirements. And there we also need to demarcate ourselves and say, hey, yes, we make a lot of things happen, but that can't be a replacement for a proper social system, or neighbourhood work, or whatnot. So, the City can't sit back and leave everything to the *Baugruppen*. (int\_7)

Housing groups thus try to navigate between highlighting all they can achieve for the neighbourhood and exempting themselves from fulfilling what they regard as duties of the city. The high expectations and demands of the City concerning neighbourhood services are thus perceived as indirect hostility, as highlighted in the use of the term "abuse" in different contexts that I encountered. This would not only demand a high investment of work and resources from the CoHo groups, but it would also privatise public duties, and in this way counter the aim of many CoHo groups and organisations to resist neoliberal developments, as expressed in their statements against the commodification of housing. One way of positioning CoHo as beneficial for broader populations and simultaneously limiting the direct services and benefits it needs to provide for the neighbourhood is to frame housing projects as exemplars or prototypes for innovative housing. These examples may be few in number but could be learned from and scaled up in the long run by the city and other actors. They often link this framing to the City's strategic planning goals. E.g., in the announcement of an event, a CoHo organisation says:

The Smart City Strategy of the City of Vienna calls for social innovation, to spare resources and maintain quality of living in the city. Who, if not the Viennese [collaborative] housing projects could be a source of such a social innovation in the area of housing? (event\_5)

To further emphasise their innovativeness, CoHo groups document and highlight when their projects are involved in exhibitions, publications, or receive awards (cf. Schikowitz & Davies, 2024). In this way, the relevance of CoHo shifts to their role model status, rather than to their number. Here, however, the danger of co-option and of misusing the projects to further the prestige of companies or to legitimate the policies and strategies of the City of Vienna is indeed acknowledged. Echoing a repeated reaction, one of my interview partners pointed out in an ironic tone:

They [building contractors and city administration] would say, "Oh, we have so much work with these mini projects"...but if you look at which projects they display in their agencies, most of them are collaborative projects. And also the showcase [CoHo] projects, that they [the representatives of the City of Vienna] show to international delegations, to prove how *cool* the City of Vienna is [laughs]. (int\_7)

Here, what annoys the interviewee besides the fact that the agencies and planners take credit for the housing projects while trivialising them at other occasions, is that by doing so, the City is buying into the

same logic of co-opting alternative models that they implicitly impute to CoHo with the “bobo accusation.” Besides posting critical comments about the City’s planning strategy and their entanglements with business actors on social media (cf. Schikowitz & Davies, 2024), the groups counteract this danger of co-option by using the neighbourhood services and physical facilities that they provide in ways that are suited to foster resistance. In other words, they are engaging in “infrastructuring publics” (LeDantec & DiSalvo, 2013) by providing “space for initiatives” (int\_3) and formats where the neighbourhood dwellers can exchange and organise and where common issues can emerge—for instance, a group that challenges car-centric planning, organises events and protest activities around this issue, and provides a physical infrastructure of non-commercial bike-sharing and repair facilities that offer and facilitate alternative mobility practices and bring together those who support these issues. While these offers could be mobilised by the City and by companies to promote how “cool” the neighbourhood is, they would simultaneously contribute to the formation and organisation of publics who resist certain policies.

In sum, to stress their broader relevance, CoHo groups present themselves as prototypes to be learned from and that can potentially be scaled up for creating more active and lively neighbourhoods. Simultaneously, to mitigate the co-option of their projects for adverse goals, the CoHo groups use their facilities and activities to mobilise the neighbourhood to create and realise alternative visions of sustainable and just housing.

#### **4.2. Establishing Expertise**

Next to the alleged challenges to their relevance, CoHo proponents often feel that their professionalism and expertise are discredited. In interviews, my interlocutors would often bemoan that building contractors, architects, and other professionals with whom they cooperated would not take their decisions and requirements seriously, and often tried to overrule them by sticking to their standard solutions, because they think “they know how it works anyways” (event\_6). It then required further interventions, arguments, and conviction to explain that certain decisions were not arbitrary “but that there was a consideration behind it” (int\_5). Similarly, the housing groups encounter hostility, for example, when in debates planners complain that housing groups would insist on their own planning decisions even against expert advice.

To counter these concerns, CoHo proponents often highlight the amount of certified professional expertise available in their groups by staging the expertise of single group members, who are architects, planners, or researchers. They often highlight their double expertise as professionals who also possess lived experiences in self-organisation as members of housing groups and other initiatives. In this way, while drawing on established sources of credibility such as certified professional expertise, they try to enlarge and shape what is regarded as legitimate expertise in relation to urban planning—e.g., I repeatedly encountered the claim that those engaging in CoHo would be “experts in democracy” (event\_3). Further, expertise in creating and maintaining sociality and togetherness is foregrounded. In one panel discussion, this was highlighted by stating that the city would “provide the vehicle-body, but the thing does not drive yet, there you need a bit more...a social body” (event\_2) that CoHo would create. Sometimes, it is even mentioned as a benefit of housing groups that they would not be too professional, that they would sometimes be “a bit naïve” (event\_5), which would let them try new things that might spark experimentation and innovation, even if they would be somehow risky or ambitious.

The public discussion events where CoHo proponents appear on the podium play a crucial role in the enactment and stabilisation of alternative forms of expertise. Often, CoHo representatives organise events

and discussion formats and invite various experts from professional realms and the city administration, as well as some representatives of CoHo groups. In this way, these persons are established as experts (cf. Grundmann, 2016; Limoges, 1993). They are subsequently invited to other events. In this way, CoHo proponents achieve a place at the table by first creating their own tables and, in this way, proving themselves as invitable. In addition, many CoHo groups and organisations emphasise their expertise by cooperating with and mobilising researchers. They are usually very open to contributing to research about their projects. Moreover, CoHo proponents increasingly set up their own research projects.

Summing up, to counter hostility concerning their expertise, CoHo proponents simultaneously highlight the certified expertise of individual members and cooperation partners, and they attempt to enact counter-expertise that builds on lived experiences in self-organization and on engagement in critical research. This not only stabilises the credibility of CoHo proponents, it also re-interprets how credibility is understood (cf. Epstein, 1996).

### **4.3. Building Trust and Reliability**

A third kind of hostility that CoHo encounters is that of city officials and professionals who are not used to working with emerging and collectively organised groups. Here, indirect hostility is based on the uncertainty of how to cooperate with unfamiliar entities and lacking practices and routines for doing so. Direct hostility is often derived from a lack of trust owed to assumptions about, and first- or second-hand experiences with, unreliable groups. I was often told that officials and professionals sometimes insisted on CoHo spokespersons who were formally entitled to make decisions for the group. This insistence is often at odds with collective self-organisation, particularly the emergent and iterative character of the formation, renegotiation, and adaptation of group structures and procedures. As a relatively recent phenomenon, the housing groups do not neatly fit into the existing municipal funding categories. Thus, for the city administration, CoHo projects are hard to grasp and categorise through formal processes, and the groups encounter a certain suspicion that they might just use certain categories strategically for their own advantages. A city representative who was sympathetic towards CoHo expressed this ambivalence between emergence and stability at a panel discussion:

There needs to be trust from the side of the City to allow for something which we can't define exactly from the beginning...but on the other hand, we also saw that it is important that those who apply [for public funding; i.e., housing groups] also live up to this trust by being really stable groups. (event\_2)

This shows that the apparent intangibility and fluidity of the groups is also a trust issue. Establishing trusting relations with city officials is often done by drawing on personal contacts between individual group members and city officials. Cultivating such personal relations requires some investment of time and effort; individuals need to be present, make themselves known, and prove their trustworthiness and reliability—“for them [the City] it needs this contact partner [from CoHo], and you need to work hard for that” (int\_7). While others acknowledge the value of these mediating persons for CoHo, these overlaps of community interests and personal interests are also regarded with suspicion, as one interviewee considered: “So, yes, that was good for us, but they also used their connections for themselves and did not communicate everything” (int\_7).

On the side of the City, some individuals who are open towards CoHo or who share specific values or political stances with a group, were ready to support them and act as gatekeepers and mediators to the city administration (which does not imply lobbying for self-interest in the sense of corruption or nepotism, but rather lobbying for a shared sense of a public good). They did provide informal knowledge about administrative procedures or put across to the city administration that “this is something that the City wants to foster...because they saw the potential of the project” (event\_5). In short: These actors trusted in CoHo and helped to mitigate the City’s hostility. Yet, “depending on the goodwill” (int\_7) of these gatekeepers and personal contacts is also something that constrains CoHo and that hinders a more general upscaling beyond case-by-case decisions, and a more active and self-determined involvement in urban development.

Beyond personal contacts, there are attempts to make CoHo as a whole more graspable and establish trustworthiness and reliability in the long run. Here, organisations that represent several housing projects play a crucial role. On the one hand, they try to convince policymakers and professionals that CoHo is reliable, they “tried to explain to them [the city administration] what *Baugruppen* are...so, when they have a procedure, what are criteria they can apply in a jury to assess? Is this a real *Baugruppe*?...So we presented them a paper, where we tried to propose a new model” (int\_7). On the other hand, there are attempts to shape CoHo to fit this model to ensure mutual trust and reliability.

Making heterogeneous and fluid groups reliable involves standardising and homogenising them to a certain extent. To define what CoHo is means to define what is not part of it. For example, in workshops, some organisational and financing models, legal forms, procedures to reach decisions, and ways of relating within the group, are promoted and recommended as especially suitable for CoHo in Vienna. Groups are encouraged to assemble their individual model from these recommended building blocks. Specific kinds of self-presentation towards the outside and even standardised ways of arguing the aims and benefits of CoHo can be observed as a form of “narrative infrastructure” (Felt, 2017) that can be used for creating recognisability and trustworthiness. At different events, I encountered almost identically phrased arguments repeatedly, and I heard the same anecdotes to illustrate them in different contexts. Also, often technical arguments were blended with political arguments (cf. Schikowitz & Davies, 2024), arguing, e.g., that certain ownership or financing models would better correspond with the value of de-commodification of housing, they would help to mitigate certain social problems that would often arise in groups, and simultaneously be more easily applicable within the Austrian context.

#### 4.4. Infrastructuring Inevitability Between Subversion and Co-Option

CoHo groups’ perception of mostly indirect hostilities and the ways they try to enact their inevitability as a response, demonstrates the co-production of participation in the ambivalent Viennese planning culture. Building on the analysis so far, I now re-examine the findings to explain how CoHo groups engage in infrastructuring activities to stabilise both their inevitability and their alternative stance.

Overall, infrastructuring appears as necessary, as the dependence on personal contacts and sizing the few opportunities for getting access to building plots and for engaging in planning strategies is perceived as problematic by CoHo proponents. One of my interviewees put that in a nutshell:

And I would say, there is a critical relation to the City....So, on the one hand, it is our aim...to create models, lighthouse projects, that are counter-models and that show that you can do housing differently

and that you can even do that without the City. But it would be even better if we could do that with the City. (int\_4)

Based on this desire to secure counter-models and to simultaneously work together with the City, CoHo also involves more long-term infrastructuring activities, to build and stabilise inevitability and resistance in specific ways. I now re-examine how infrastructuring, which includes material, organisational, and narrative elements (Schikowitz et al., 2023), is done to stabilise relevance, expertise, and trust, and how boundary objects (Star & Griesemer, 1989) figure in it.

First, CoHo creates material facilities, platforms, and community offers. They serve as boundary objects, as for the City they represent neighbourhood services that contribute to a lively and peaceful togetherness, especially in city development areas. In addition, these offers are used as assets that valorise a neighbourhood for economic purposes. Yet, simultaneously, the facilities and events are sites where issues and publics can emerge and that could become focal points for resistance, e.g., against the commodification of public spaces (cf. Bjögvinsson et al., 2012; Corsín Jiménez, 2014; LeDantec & DiSalvo, 2013).

Second, to contribute to legal frameworks and funding categories, CoHo proponents engage in the development of definitions, standards, and models. These constitute another set of boundary objects that facilitate interaction between administrative and professional actors, and housing groups. For the City, these categories and definitions make CoHo groups more interpretable in an administrative sense, and they create a certain reliability and calculability, which allows the city to include them in planning strategies and urban development. For the housing groups, the categories likewise facilitate organisation and make internal and external collaborations more efficient. Yet, they provide a means for protecting CoHo from excessive demands, as well as arbitrariness, by allocating clear responsibilities and rights.

Third, infrastructuring activities comprise the rehearsal of shared stories and arguments as “narrative infrastructures” (Felt, 2017), that interweave a shared reference to the past of Viennese (housing) policies with references to innovativeness and togetherness of CoHo (cf. Sepehr & Felt, 2023). These narrative infrastructures facilitate cooperation, but they include struggles over interpretations of togetherness, solidarity, and the distribution of responsibilities between the City and self-organised citizens. In some settings, such as strategy documents, these conflicts are put aside to allow for cooperation, while in others, such as debates, protest, and political initiatives, they are staged to maintain the respective identity and political stance of each actor in agonistic ways.

As a result, most of the newer housing groups in Vienna have adopted what has been called the “Viennese model” of CoHo (Lang & Stoeger, 2018), which consists of variations and combinations of specific material and architectural forms, organisational building blocks, as well as a specific way of narrating and presenting themselves. Using these models makes initiating and organising CoHo easier and more efficient. In discussions and interviews, this is often described as “not needing to invent the wheel anew.” While for the first groups in Vienna it took about a decade from the group formation until moving into their houses, the newer projects can be realised in only a few years. This efficiency makes the groups more accessible for those interested, and more reliable and predictable for external actors from the city administration and professional firms who cooperate with housing groups, helping to create inevitability into planning processes. However, standardisation and infrastructuring might also reduce heterogeneity and diversity of groups, as it



not only mobilises external actors but also mobilises and disciplines CoHo groups themselves to fit this model and to make themselves invitable.

In sum, the infrastructuring activities in which CoHo in Vienna engages, allow for cooperation of several actors but also allow each to maintain their own agendas and identities. Sometimes, these agendas overlap (as with the standards and definitions), sometimes they subvert each other in subtle ways (as with the neighbourhood offers), and sometimes they are in conflict (as in the case of narratives).

## 5. Conclusion

Throughout the findings, the multiple, ambivalent, and shifting relations between the various actors involved in the governance of the City of Vienna, and the different CoHo groups and proponents, became evident. This relates to indirect hostilities stemming from entrenched values and obdurate practices (Hommels, 2005) that have been established during a long tradition of expert-based and ideologically driven planning policies of the social democratic city government, which has even been described as paternalistic (Novy et al., 2001; Rumpfhuber et al., 2012; Sepehr & Felt, 2023). For this reason, CoHo proponents try to infrastructure inevitability by establishing their relevance, expertise, as well as trust and reliability. They do so in ways that are compatible with the City, but that simultaneously are true to their own issues and values that might challenge City policies. Thus, mimicking the City's indirect ways to frame and foreclose certain ways to participate, CoHo does not create inevitability as an end in itself, but as a means to contribute to and to subvert the City's housing policies and realise alternatives. In this sense, not only is the City both hostile and open towards CoHo, but CoHo is simultaneously hostile and open towards the City, co-producing hostilities and forms of participation that are specific for the indirect and ambivalent Viennese participation culture.

Thus, infrastructuring of CoHo in Vienna can be regarded as creating and stabilising agonism (Farías, 2016; Mouffe, 1999), which does not necessarily strive for consensus but creates the conditions for an ongoing political struggle, where coalitions and interactions are possible but are also constantly re-negotiated. In this way, the infrastructuring activities maintain housing as a political issue, rather than reducing it to a technical problem. Such a politicisation overall caters to both activist and municipal stances and might help to delay neoliberal developments towards commodification and financialisation of housing.

Yet, while infrastructuring serves to maintain resistance, the literature on how civic actors make themselves heard in planning processes hints at the fact that official recognition often goes along with a certain internal homogenisation and exclusions of the less compatible elements and aspects of a movement (cf. Bijker & Bijsterveld, 2000), and thus might involuntarily contribute to a reinforcement of established practices and power structures. Similar observations have been made about CoHo groups that are less compatible with the City's expectations and that rather try to stay unobtrusive in a hostile environment (Lang & Stoeger, 2018; Schikowitz & Pohler, 2024). These groups might thus be marginalised in the CoHo community and in planning (although also less visible participation can have an influence). The standardisation involved in infrastructuring might bear the risk of homogenising CoHo internally and excluding aspects of CoHo that do not lend themselves as boundary objects (Slota & Bowker, 2017). I would thus make a case for seeking ways to maintain CoHo's diversity, next to infrastructuring inevitability and resistance in one specific way, including an ecology (Chilvers & Kearnes, 2020) of different collaborative forms and models that go along with diverse publics and issues.

The case of (un-)invited participation of CoHo in Vienna demonstrates the subtle mechanisms in which indirect hostilities co-develop with specific forms and practices of participation based on managing boundaries that attune to, navigate, and negotiate the ambivalent environment of the Viennese planning culture.

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### Conflict of Interests

The author declares no conflict of interests.

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### About the Author



**Andrea Schikowitz** is a senior postdoc researcher at the Department of Science and Technology Studies, University of Vienna. Her research addresses the encounter of diverse ways of knowing and how this is related to possibilities for change. She has investigated this question by analysing various settings—such as transdisciplinary sustainability research, public governance, urban living labs, and collaborative housing. Her current work is on (digital) knowledge practices in distributed urban planning and controversies.

# Citizens in Distress: A Case Study on Public Participation During the Covid-19 Pandemic in Finland

Mikko Värttö 

Faculty of Social Sciences, University of Turku, Finland

**Correspondence:** Mikko Värttö ([mikko.vartto@utu.fi](mailto:mikko.vartto@utu.fi))

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## Abstract

In emergencies, public participation can perform a positive function by raising public awareness of the potential harms and injustices that may have resulted from emergency measures and policies. In this way, public participation can contribute to democratic crisis management, and also legitimise democratic institutions more broadly. However, emergency conditions can challenge these participatory practices, undermining citizens' ability to influence crisis management. To investigate this phenomenon, this article studies how ordinary citizens participated in the management of the Covid-19 pandemic. The article focuses on Finland, a critical case because its response to the pandemic is often considered successful in international comparison. In the analysis, data on various formal and informal forms of public participation are considered and their impact on emergency response is assessed. The findings show that although multiple forms of public participation were in place, the authorities used them selectively and hesitantly. Also, public participation was often diminished to an advisory role or channelled through established civil society actors, such as labour market organisations. Due to this lack of critical voices in public arenas, citizens decided to bypass formal routes of public participation to express their concerns through civic activism in informal channels. These concerns materialised in campaigns, protests, and demonstrations against emergency measures and policies. While much of the existing literature focuses on the negative effects of civic activism, such as spreading misinformation and undermining official measures, this article argues that informal public participation, such as civic activism, can complement formal decision-making measures during emergencies, thus contributing to more effective and democratic crisis governance.

## Keywords

civic activism; Covid-19 pandemic; crisis management; emergency; public participation

## 1. Introduction

During the Covid-19 pandemic, citizens staged large-scale global protests and demonstrations against governments and their handling of the health crisis. This public dissent towards emergency measures and policies was often channelled through pre-existing groups and movements. However, pandemic policies also initiated new social movements, bringing together people from diverse backgrounds and agendas who employed tactics that diverged from conventional social movements. For example, grassroots groups mobilised to support neighbours, elderly people, individuals with disabilities, precarious workers, and Indigenous communities (Milan & Treré, 2022). In addition, these groups engaged with different online, offline, and hybrid repertoires of contention and collective action, such as flash mobs, teach-ins, and digital blockades (cf. Chenoweth et al., 2020; Petitjean, 2022).

On the one hand, grassroots activism can play a critical role in responding effectively to an emergency. Social groups and movements can channel and legitimise emotions such as moral pain, anger, indignation, and compassion (Gravante & Poma, 2022). Moreover, localised grassroots movements in cities and neighbourhoods can build and strengthen solidarity, resilience, and resistance in communities, and also steer attention to issues that may be neglected during an acute crisis. For example, some social movements have underlined the centrality of environmental and climate justice in coping with the pandemic. Others have highlighted the potential of a solidarity economy and new sociopolitical agendas (Bringel & Pleyers, 2022, p. 8). On the other hand, however, various scholars have demonstrated how social groups and movements have provided a platform for conspiracy theories and “alternative facts” during the pandemic, which potentially hampered effective emergency responses, undermined public compliance with chosen policy measures, and decreased trust in public authorities (Gupta et al., 2022; Pummerer et al., 2022; Romer & Jamieson, 2020; Soveri et al., 2021).

To mitigate these adverse tendencies, governments have applied various repertoires or strategies to cope with activists, which can be broadly classified into two approaches. The first approach refers to formal forms of public participation in which officials invite citizens to participate in crisis governance in a constructive manner, for example, by providing them a lobbying position. With this strategy, the authorities “hug extremes to death”: an approach that includes participation from even the most radical movements to undermine their untamed potential (Koskimaa et al., 2021, p. 9). The second approach refers to more hostile strategies to undermine the legitimacy of activists as a means to downplay their credibility in the public eye. In some cases, authorities have publicly denounced these activists as “corona denialists” and “anti-vaxxers” (cf. Mäkinen, 2023). For example, in Finland, a research professor at the Finnish Institute for Health and Welfare called the Eeroon koronasta network, an independent group of experts, a “club of lunatics” (*hörhöjen päiväkerho*) that aims to spread conspiracy theories and decrease trust in public authorities (Vuorelma & Lehtonen, 2024).

In the aftermath of the pandemic, these findings show that the research investigating democratic governance in a crisis would benefit from a more nuanced understanding of democratic participation. An analysis of the alternative forms of public participation that emerged during the pandemic can reveal ways to revitalise democratic politics (Youngs, 2023; Youngs et al., 2021). The ultimate question that compels much of the post-pandemic research exploring this issue is: How can current democratic systems be developed to create meaningful ways for citizens to participate and get involved in emergency response



situations? This task is linked to the recent search for more experimental, reflexive, anticipatory, and responsible forms of participation in science and technology studies (Chilvers & Kearnes, 2020).

Following the above aspirations, this article studies how ordinary citizens participated in the management of the pandemic in Finland. The analysis tracks different modes of participation through which citizens, civil associations, and other civic actors attempted to influence emergency measures and policies. Finland is an important research case because the existing model of participatory government already offered various routes for citizens to participate in politics outside of elections. Since these channels were functional even during the Covid-19 pandemic, decision-makers potentially had a formal model for understanding citizens' needs and concerns about the crisis response already in place. However, interestingly, the pandemic illuminated the limited extent to which citizens actually could influence emergency measures and policies, which may have contributed to the rise of more informal forms of civic activism that emerged during the pandemic.

Another reason for a single case study is that, historically, Finland has been ranked highly in international country comparisons, both with regard to democratic qualities and also pandemic response (e.g., Scheinin, 2022). One factor that contributed to the successful pandemic response was that, similarly to other Nordic countries, Finland is a high-trust society (Kestilä-Kekkonen et al., 2022). This factor likely contributed to the efficacy of Finland's early response to the Covid-19 pandemic, as citizens complied with the emergency measures and policies. However, the situation changed after the initial phase of the pandemic, when criticism of emergency policies and measures began to surface (Ketola, 2024). The growing dissent toward the government's pandemic response over the course of the pandemic, therefore, may have been an indicator of the deficits in the democratic governance of the crisis, and thus poses an important area for further analysis.

To delineate a diversity of formal and informal participatory processes in Finland during the Covid-19 pandemic, this article adopts the following structure. The next section will draw a comparison between constructive democracy and counter-democracy. While the former refers to various formal forms of public participation, the latter is related to the more informal modes of participation, such as civic activism, protests, and demonstrations. Both forms of participation have qualities that can contribute to the democratic governance of crises. Drawing from this overarching idea, the various participatory processes in Finland are analysed, and their impact on emergency governance is assessed. The analysis was based on a multi-method research design where data from different sources was accumulated, analysed, and cross-checked. The conclusions will introduce and discuss the main findings and propose improvements for democratic systems in Finland, which may be generalised to apply elsewhere.

## 2. Between Constructive Democracy and Counter-Democracy

In recent years, public interest in democratic innovation has increased among scholars, policymakers, and the wider public. Democratic innovations refer to institutions “specifically designed to increase and deepen citizen participation in the political decision-making process” (Smith, 2009, p. 1). In practice, democratic innovations can allow citizens to participate in public spending through participatory budgeting; to propose new political agendas through citizens' initiatives; and to plan proposals for decision-makers with other citizens in deliberative mini-publics. As the use of these democratic innovations in various contexts has

increased, a new field of study has emerged that explores ways of institutionalising democratic innovations to create better connections between existing and emerging political and administrative processes (Dean et al., 2020; Macq & Jacquet, 2023; Warren, 2009, 2017). One argument for further institutionalisation of citizen participation is that it would prevent authorities from ignoring the outcomes and recommendations produced by the participatory and deliberative processes.

Yet some critics have questioned the institutionalisation of public participation. According to these critical voices, top-down participatory initiatives may represent a gesture designed to create the illusion of democratic process (Fuji-Johnson, 2018) or to give the appearance of engagement without producing any meaningful change in process (Moore, 2017). For instance, public participation exercises have been described as “technologies of elicitation” (Lezaun & Soneryd, 2007). From this perspective, democratic innovations can be considered “extractive industries” that aim to generate certified “public opinion” to increase government productivity (Lezaun & Soneryd, 2007, p. 280). Further, some authors also have raised concerns about the political use of democratic innovations (Lafont, 2017) or their instrumentalisation for governmental purposes (Moore, 2017).

The most pressing criticism highlights the strength of civic activism and civic actors in democratic politics. For example, Young (2001) has criticised democratic innovations scholars for forgetting the democratic strengths of social movements. Della Porta (2020) illuminates these strengths, arguing that social movements can nurture innovative ideas, and also generate counter-expertise and new forms of knowledge. Rosanvallon (2008, p. 314) argues that a democratic system requires not only the “positive” forces of deliberation and reflection but also the “negative” power and challenge of counter-democracy. It is the role of social movements to contribute to this “constant evaluation and criticism of the actions of the government by the governed” (Rosanvallon, 2008, p. 39).

To expand on the importance of the role of civic activism in democratic politics, Rosanvallon (2008) distinguishes between constructive and constraining power invested within democracy and counter-democracy. This postulation entails that constructive and constraining powers are included in the mix of democratic governance (Rosanvallon, 2008, p. 314). Whereas democratic innovations, such as deliberative mini-publics, are more strongly inclined to constructive politics, counter-democratic forces, such as social movements, can play a nonconstructive and constraining part in the democratic system’s mix (Hendriks, 2022). Thus, both constructive and constraining powers are needed in the democratic system to nourish the varied repertoires and values required for democratic legitimacy.

In recent years, a similar discussion about the constructive and constraining roles of public participation has taken place in public administration scholarship. Over the last 30 years, governments worldwide have invited private and civic actors into the governance processes to improve the effectiveness, legitimacy, and innovativeness of public governance (Peters et al., 2022, p. 969). These collaborative governance initiatives aim to establish stronger ties between public authorities and civic actors, and thus support communities and individuals to take a more prominent role in their own well-being. Whereas some consider these arrangements primarily as sources for further agency and self-authority, others see them as “technologies of community” (Rose, 1999, p. 188), where local communities are produced as close allies to authorities (Nousiainen & Pykkänen, 2013).

Due to the “collaborative turn” in public governance, government officials, as well as researchers, have begun to focus on the political and democratic implications of involving citizens in processes of public governance (Peters et al., 2022, p. 969). This new focus has stimulated interest in “political metagovernance,” which involves elected politicians making politically charged decisions, for example, about overall goal setting, the financial framework, and the exclusion of particular actors (Sørensen & Torfing, 2009). In the last case, social actors from collaborative governance networks who do not comply with the pre-set requirements established by public authorities may be excluded. On this account, arrangements for network collaboration, co-creation, and co-production could also be seen as practices of exclusion and domination.

Some authors claim that the excessive focus on collaborative governance has sidelined the agonistic tendencies within urban communities. Therefore, they have proposed various modes of counter-governance as a response to collaborative governance. For example, using Rosanvallon’s (2008) postulation of three democratic counter-powers as a framework, Dean (2018) explores new ways for citizens to adopt a defensive relation to institutional actors to engage in counter-governance. According to Dean, the practices of prevention, oversight, and judgment can complement the existing forms of collaborative governance and provide ways to settle and solve conflicts that often characterise contemporary urban governance.

To conclude, the participatory turn has impacted the realms of politics and public administration in recent decades. This turn has transformed the relationship between citizens, politicians, and public administrators. Whereas politicians and public administrators seek to constrain citizens within formal participatory practices, activists, and those who oppose institutionalising efforts, may consider these practices too restrictive and thus may seek alternative, informal ways to affect public policy. Moreover, due to the inefficiency of the existing participative channels, people may participate in protests and demonstrations to make their voices heard. Especially in a crisis, these modes of counter-democratic politics may be the only option for citizens to impact emergency policies and measures.

### 3. Public Participation During the Pandemic

Much of the research literature on the Covid-19 pandemic has focused on the centralisation of decision-making in the hands of politicians, administrators, and experts. Some assessments of the pandemic response have shed light on the ways in which governmental responses to the pandemic have further intensified democratic erosion and authoritarian tendencies in different countries (e.g., Guasti, 2020; Merkel & Lührmann, 2021; Poyet et al., 2023). The research has drawn attention to the political leaders who have exploited the pandemic as a stalking horse for practices that undermine the capacity of democratic institutions to monitor the executive powers (Youngs, 2023). For example, in many countries, parliamentary proceedings were temporally suspended or restricted (Chiru, 2024; Värttö, 2024).

In response to the government’s excessive use of emergency powers during the Covid-19 pandemic, a new wave of civic activism emerged. Various activists and civic groups criticised the strict emergency measures and policies implemented during the pandemic. Some observers have argued that this civic activism put critical pressure on governments, and thus helped to improve their Covid-19 strategies (Youngs, 2023). For example, in some countries, the Covid-19 pandemic-related protests intensified pressure for democratic change (Carnegie Endowment for International Peace, 2024). More critical voices, however, consider protests and demonstrations as a continuation of the rise of global far-right populism (Vieta, 2020).

Despite the fact that much of the civic activism that emerged during the pandemic embodies the characteristics of constraining power, there are also signs of more collaborative forms of civic activism that occurred during the state of emergency. In many places, new forms of citizen activism appeared, such as neighbourhood, mutual aid, voluntary, and community groups. On many occasions, these groups collaborated with public authorities to provide complementary services for people who were in need during the pandemic (Hall et al., 2021). By having established close connections with the local communities, these groups could reach vulnerable individuals who may have otherwise been left unprotected.

During the pandemic, many countries also took advantage of democratic innovations, such as deliberative citizen assemblies, to bring together randomly selected citizens to deliberate and make recommendations on aspects of the pandemic. For example, the Climate Assembly UK and the French Citizens' Convention on Climate—both large-scale randomly selected deliberative bodies—moved online to hold special sessions to consider the Covid-19 crisis and to generate recommendations for its management (Afsahi et al., 2020). Together with collaborative and community-led approaches, these processes created innovative spaces for citizen participation, deliberation, mobilisation, and organisation (Lacelle-Webster et al., 2021).

There are inherent positive forces in democratic practices that can facilitate the management of crises, and then promote recovery based on the results. Crisis management scholars have long acknowledged that, in a state of emergency, crisis management must be both effective and democratic (Boin et al., 2016). The legitimacy of the crisis response is not only about effectiveness but also about participation, impartiality, and due process (Lægreid & Rykkja, 2019; T. Christensen et al., 2016). Thus, citizens' views of the legitimacy and acceptability of suggested measures are central preconditions in effective crisis management. When citizens consider the emergency measures justified, they are more willing to comply with the restrictions and recommendations (Fung, 2021; Smith & Hughes, 2021).

Although the benefits of public participation are well acknowledged in the research literature, the practical constraints during emergencies can pose challenges for meaningful interactions between authorities and citizens. Emergencies are exceptional situations underscored by threats, urgency, and uncertainty (Boin et al., 2016). Therefore, there might be an urgent need to respond swiftly to severe threats to citizens' health and well-being. In those circumstances, the authorities may be tempted to circumvent normal democratic procedures to prevent the most serious consequences of the crisis from materialising. To what extent these actions have been justified and also how they can affect the crisis response are central issues in post-crisis research on emergency measures and policies.

#### 4. Data and Methods

This article aims to contribute to the research literature on the functioning of democratic institutions during the Covid-19 pandemic by studying how citizens and civic actors have influenced the pandemic response in Finland. One way to study different participatory practices is to assess their capacity to fulfil different democratic values. Democratic literature often enlists enlightened understanding, inclusion, influence, equality, and transparency among the most characteristic qualities of a democratic political system (e.g., Dahl, 2000; Fishkin, 2009). However, the norms and values of the democratic processes depend on the mode of democratic governance they represent. For example, participatory methods are designed to make public decision-making more inclusive by reaching out to groups who typically participate less in public

affairs, and also more equal by levelling opportunities to contribute and influence public policymaking (Fung, 2021). Deliberative methods, on the other hand, can inform public policies by giving an insight into an “enlightened” citizen’s opinion (Landemore, 2012). In exceptional circumstances, such as crises, adopting deliberative norms in the public domain may be crucial in reducing misinformation (Chambers, 2021).

In this article, public participation is understood in broad terms, which include an array of practices based on direct, participative, and deliberative democracy, as well as collaborative governance and civic activism. Rather than evaluating each mode of participatory practice using a single analytical framework, this study evaluates the democratic values of each practice separately and then estimates their main strengths and weaknesses in relation to democratic governance. The reason for not using a specific analytical framework is that in this article, democratic innovations are studied alongside collaborative governance and civic activism, which originate from different theoretical backgrounds. Even though these theories of democratic governance may share some broad principles, such as equality, inclusion, and freedom, they interpret these principles in different ways and promote different versions of them (Hendriks, 2022; Jäske & Setälä, 2020). Therefore, the complexity within these models makes finding common terminology that would allow building an analytical framework for studying different modes of democratic participation impractical for this research.

The analysis was based mainly on data obtained from government-sponsored websites. These data include information about the parliamentary hearings, the crowdsourced law-making processes, and citizens’ initiatives during the most critical phase of the Covid-19 pandemic. The numerical data collected from the websites were analysed using descriptive statistics. The textual media material consisted of news articles ( $n = 16$ ) about participatory processes, protests, demonstrations, and voluntary groups, which were thematically coded to recognise different actors and their main objectives. In addition, the analysis relied on a number of official reports on emergency responses and also on scientific publications published before this article. To increase the validity of the study, information from multiple sources was then accumulated, analysed, and cross-checked. Table 1 summarises the primary data sources and methods.

## 5. Results

### 5.1. Formal Participatory Processes

Much of the Covid-19 pandemic-related public participation in Finland occurred within the framework of formal processes. Between 2020–2022, the Finnish government issued altogether 161 pandemic-related governmental proposals, which introduced new policies and measures to diminish the effect of the Covid-19 virus on public health. All pandemic-related governmental proposals were subjected to *parliamentary review in parliamentary committees* before finalising the proposals. Within these committees, the committee members could discuss the proposals and request comments from ministries, research institutes, experts, and civil associations. Altogether, 3,401 statements on emergency measures and policies were submitted during the Covid-19 pandemic.

By making the law-making process open to the public, the parliamentary committees could have ideally increased the inclusiveness and transparency of political decision-making. However, when considering the participants in the consultation rounds, the implementation of these democratic values remains limited.

**Table 1.** Summary of data and methods.

Participatory process	Data	Methods
<b>Formal</b>		
Public hearings in parliamentary committees	3,401 statements issued on 161 governmental acts; data obtained from the official website of the Finnish parliament	Descriptive statistics
Crowdsourced law-making	30 drafts of governmental acts issued on the crowdsourcing platform Lausuntopalvelu.fi; data obtained from the official website of the Finnish parliament and Lausuntopalvelu.fi	Descriptive statistics
Citizens' initiative	10 pandemic-related citizens' initiatives, data obtained from Kansalaisaloite.fi; media material	Descriptive statistics; content analysis
Deliberative mini-public (regarding the Covid-19 pandemic)	Previous research, main source Leino et al. (2022)	Literature review
Lockdown Dialogues	Previous research, main source Henttonen (2022)	Literature review
The Citizens' Pulse survey ( <i>Kansalaispulssi</i> )	30 survey rounds between 2020–2021; data obtained from Statistics Finland	Descriptive statistics
Communication measures for information sharing	Previous research, main source Hakala and Ruggiero (2022)	Literature review
Collaborative projects	Previous literature, main source Hakala and Ruggiero (2022)	Literature review
<b>Informal</b>		
Voluntary work	Media material	Content analysis
Protests and demonstrations	Carnegie Global Protest Tracker (Carnegie Endowment for International Peace, 2024); media material	Descriptive statistics; content analysis
Information campaigns	Previous research, main sources Mäkinen (2023) and Vuorelma and Lehtonen (2024)	Literature review

The review of the statements shows that the consultation rounds tended to favour public organisations, such as ministries and research institutions. Of all the statements, only roughly one-third (1,046) were written by non-governmental actors. Of these actors, the majority of the statements were from well-established interest groups, such as labour market organisations. It could be regarded as symptomatic that the Finnish National Youth Council, perhaps the only voice for the future generation, was heard only three times by the parliamentary committees during the pandemic. This finding aligns with previous research by Vesa and Kantola (2016), who claim that organisations representing established institutions, companies, and employers are involved most closely in policy preparation.

Some Covid-19 pandemic-related laws were also subjected to public feedback through the *crowdsourced law-making* platform Lausuntopalvelu.fi, where citizens and civic actors could read and comment on the drafts. Crowdsourced platforms can have the capacity to bring a greater diversity of voices to the table than more traditional procedures, such as parliamentary hearings. However, the analysis showed that this opportunity was underutilised. Altogether, only 30 of 161 pandemic-related drafts were issued on the platform. This observation shows that only under 20 percent of pandemic-related governmental proposals

were submitted for public scrutiny. This difference between Covid-19-based legislative drafting and other legislative projects is considerable and statistically significant (Jukka et al., 2022).

Two of the drafts issued on the Lausuntopalvelu.fi platform concerned the government's proposal for a corona certificate (*koronapassi*) that would have made it possible to restrict the lives of those citizens who had decided not to receive the vaccines. These proposals were highly controversial and gained more comments than any previous drafts in the history of crowdsourced law-making. The review of the comments showed that although some of the commentators wrote on behalf of their company or association, most of the commentators were ordinary citizens who were speaking for themselves. The preliminary analysis also indicated that most comments criticised the initiative for various reasons, such as ineffectiveness, social consequences, discrimination, and violation of basic human rights. It could be suspected that the public criticism of the corona certificate was partly responsible for the eventual abandonment of the initiative. Still, the actual impact is difficult to assess and remains unclear.

Other participatory procedures also remained functional during the Covid-19 pandemic. One of these, the *citizens' initiative*, entails that every initiative that reaches the threshold of 50,000 signatures will receive a parliamentary proceeding. Ten pandemic-related citizens' initiatives were made, of which three reached the required 50,000 signatures to proceed to the Finnish parliament. However, only one of these initiatives—regarding a rise in nurses' salaries—eventually proceeded to parliament. This initiative did not directly influence the nurses' income, since politicians cannot influence salary negotiations. Nevertheless, the initiative was discussed in the media and likely put pressure on future negotiations (Tanner & Pikkarainen, 2020). This observation aligns with previous research indicating that, despite their limited impact on the legislature, citizens' initiatives can often change the media agenda and bring attention to issues that citizens consider important yet remain underrepresented in parliament (e.g., H. S. Christensen et al., 2017). The other two initiatives regarding the corona certificate never proceeded to the parliament because the government withdrew its proposal.

Whereas participatory initiatives and crowdsourced law-making could be considered examples of participatory democracy, more deliberative processes also occurred in Finland during the pandemic. For instance, *deliberative mini-publics*, institutions where a "diverse body of citizens is selected randomly to reason together about an issue of public concern" (Smith & Setälä, 2018), were organised. In Finland in 2021, a mini-public was formed with the objective of evaluating the existing emergency policies regarding the Covid-19 pandemic and the different health and social impacts. Even though the mini-public was primarily experimental and had no direct policy impact, the research shows that mini-publics can provide productive circumstances for citizens to scrutinise emergency policy proposals produced by the authorities (Leino et al., 2022).

Another citizen-focused experiment in Finland consisted of 296 *Lockdown Dialogues* to increase the policymakers' understanding of everyday life during the pandemic. These dialogues were organised in 2020–2021, and provided a platform for over 2,000 citizens to share their experiences of the pandemic (Henttonen, 2022). Public authorities received summaries of the dialogues, but it is questionable whether they affected the crisis management response. Also, the dialogues did not follow the basic requirements of deliberative processes regarding participant selection and information sharing. For example, the participants were selected through an open call, and no prior information was given to the participants before the



event. Therefore, the dialogues functioned more as a platform for peer support rather than as a form of political participation.

To map citizens' opinions and feelings about the pandemic measures, the government launched the *Citizens' Pulse survey (Kansalaispulsse)* in the first year of the pandemic. The survey was repeated every three weeks during the pandemic, and provided a means for citizens to give feedback on pandemic policies to authorities. It included questions about trust in different authorities, perceptions of crisis communication, and emergency policies and measures. Therefore, the survey allowed the authorities to assess how the citizens perceived the measures taken during the pandemic. However, there is limited evidence that the survey results influenced the actual emergency response. Only one of the government's policy proposals referred to the survey results (HE 74/2022), which may indicate general indifference or dismissal of the feedback. On the other hand, some findings from the survey were widely discussed in the media, demonstrating some impact on the media agenda (e.g., Hyytinen, 2022).

To disseminate information about pandemic situations and emergency measures, the government applied a number of *communication measures*. Approximately 100 press releases were published during the early stage of the corona crisis (12.3.2020–31.1.2021). Ministries published approximately 1,500 coronavirus-related bulletins and online news articles. Government briefings and weekly joint meetings of the Ministry of Social Affairs and Health and the National Institute for Health and Welfare were held a total of 140 times, and were live-streamed by the national broadcast company. Also, video clips and news were shared through the government's social media accounts (Hakala & Ruggiero, 2022). Information sharing is essential in crisis management because it prevents rumours from spreading that can undermine collective efforts to manage an emergency. However, from the perspective of public participation, it is considered the weakest form of participation, as it only allows citizens to access information determined by the authorities (Fung, 2006). It is also uncertain how centralised crisis communication functions effectively in the current fragmented media environment (Uutela & Väliaverronen, 2023).

In addition to democratic innovations and other participatory processes, more *collaborative efforts* emerged in Finland during the pandemic. In 2020, the Finnish government launched a collaborative project called Finland Works (*Suomi toimii*). The project aimed to produce a series of communication campaigns, videos, podcasts, events, and other collaborative projects in cooperation with civil society actors. Between 2020 and 2021, over 180 non-governmental actors, churches, media, municipalities, private companies, and social media influencers participated in the project. This strategy positioned civic actors, local communities, and private companies as intimate allies of the public authorities in the fight against the coronavirus. However, despite the extensive resources spent on the project, it failed to receive widespread public attention and remained mainly an information sharing channel for public authorities (Hakala & Ruggiero, 2022). It also allowed authorities to exclude those actors from the project who did not follow the public authorities' values or who deviated from the official emergency policies and measures.

## 5.2. Informal Participatory Processes

Outside the formal participatory procedures and collaborative governance, which rely on cooperation between public authorities and citizens, a new wave of civic activism emerged in Finland during the pandemic, which took shape in many informal arrangements. Similarly to other European countries, a myriad

of *voluntary groups* appeared in Finland after the Covid-19 outbreak (Tillaeus, 2020). These groups comprised a loose network of individuals who already often organised through social media. In many cases, the voluntary work was organised through church organisations or humanitarian aid organisations such as the Red Cross, which has extensive experience coordinating large numbers of volunteers in emergencies (Osmala, 2021).

In addition to voluntary groups, more contestatory forms of activism emerged in Finland during the pandemic. In a global comparison, Finland stands out among the countries least affected by anti-government *protests and demonstrations*. The Carnegie Global Protest Tracker lists 51 large-scale Covid-19-related demonstrations globally (Carnegie Endowment for International Peace, 2024). In Finland, demonstrations against pandemic policies and measures were rare. Only a few of these demonstrations, including Convoy Finland, a national adaptation of the global Freedom Convoy protests, gathered more than 2,000 participants. Two demonstrations were organised by actors in the cultural sector who criticised the focus of the government's measures on the cultural sector in particular (Jaulimo, 2022; "Pysäyttävät kuvat," 2021).

Although there was no society-wide social movement against the pandemic response in Finland, various pop-up groups and networks emerged soon after the pandemic outbreak. These groups share similar characteristics: They are internationally oriented and they use social media as an essential recruitment and information sharing platform. During the Covid-19 pandemic, activists organised *information campaigns* to contest the emergency response. These activists criticised the public authorities and provided alternative information on Covid-19-related issues, mainly through social media (Väliverronen et al., 2020). In this manner, the activists tried to pressure the government to change its crisis management approach.

One of the groups that emerged during the pandemic was the Getting Rid of Corona (*Eroon koronasta*) network, a group consisting of "worried physicians, scientists, and experts who found each other on social media" (Eroon koronasta, 2020). The network contested the pandemic measures to some extent by pushing the government to adopt more drastic measures to suppress the pandemic. For example, the network gained publicity for its report highlighting the benefits of face masks, which undermined the official policy of the health authorities. However, after the initial phase of the pandemic, public authorities, researchers, and journalists began to criticise the network and its communication style, and to question its role as a pandemic authority (Vuorelma & Lehtonen, 2024).

In summary, the modes of public participation during the Covid-19 pandemic included both formal and informal participation. In the analysis, the main strengths and weaknesses of the participatory processes were identified. Table 2 summarises the modes of public participation during the pandemic. It shows that informal forms of participation complemented the formal participatory processes by engaging citizens outside the reach of formal processes. In addition, by giving a platform for more critical voices and alternative information, civil society actors may have increased the epistemic capacity of the democratic political system.

**Table 2.** Summary of modes of public participation during the pandemic.

Participatory process	Strengths	Weaknesses
<b>Formal</b>		
Public hearings in parliamentary committees	Direct interaction between civil society actors and authorities. Clear connection to decision-making.	Favours well-connected and organised groups.
Crowdsourced law-making	Provides a means for direct participation in law-making processes.	Uncertain and unclear impact on decision-making. Used selectively by the authorities.
Citizens' initiative	Chance to impact political agenda-setting and bring attention to issues that citizens consider important.	Initiatives do not proceed to the parliament.
Deliberative mini-public (regarding the Covid-19 pandemic)	Provides good circumstances for the scrutiny of policy proposals.	No connection to decision-making processes.
Lockdown Dialogues	Provide a platform for exchanging information and sharing experiences.	Uncertain and unclear impact on decision-making.
The Citizens' Pulse survey ( <i>Kansalaispulssi</i> )	Provides feedback to authorities.	Used in an advisory role. No clear impact on decision-making.
Communication measures for information sharing	Spreading information and counteracting misinformation.	Information may not reach all groups of people.
Collaborative projects	Building connections between civil society actors and authorities.	Exclusion of civil society actors who do not share the values of the authorities.
<b>Informal</b>		
Voluntary work	Complementing public services. Providing meaning and peer support for participants.	No direct connection to decision-making processes.
Protests and demonstrations	Bringing attention to issues that citizens consider important.	May be subject to mis- and disinformation. Lack of direct impact.
Information campaigns	Broadening the scope of alternatives, questioning the authorities, and scrutinising the public policies.	May be subject to mis- and disinformation. Lack of direct impact.

## 6. Conclusion

Previous literature on public participation during the Covid-19 pandemic has been extensive; however, few contributions have systematically mapped and assessed the participatory processes. To provide a more comprehensive analysis of public participation during the pandemic, this article studied the various *formal and informal forms of public participation* that coexisted in Finland after the Covid-19 outbreak. These practices allowed citizens to have a say in emergency policies, participate in implementing them, and help society recover from these exceptional circumstances. The results of the analysis can be summarised in four main findings.

Firstly, the analysis of formal forms of public participation shows that many modes of public participation were in place in Finland that allowed citizens and civil society actors to influence emergency measures

and policies. These processes have the potential to strengthen the democratic governance of pandemic politics if used in a timely and appropriate fashion. However, this potential was not fully realised, and therefore the participatory practices were only partially utilised. For example, only a small percentage of the pandemic-related governmental proposals were subjected to public scrutiny and feedback on crowdsourced platforms.

Secondly, the analysis shows that formal modes of public participation have remained mostly in an advisory role in Finland. This finding may manifest the dominant position of public administration in Finnish society, where the politicians and administrators hold a position of authority and citizens typically take a backseat in public affairs. Finnish public administration is characterised by an attitude where the administrators often doubt the capacities of lay citizens to participate in collective decision-making on complex issues (Värttö, 2022). This attitude may become compounded in turbulent times when the urgency and uncertainty of emergency policies and measures becomes imminent. Thus, the hesitance to involve citizens may indicate the prevalence of the myth that citizens panic easily in a disaster. However, studies have consistently shown that citizens tend to act quite rationally, even in the most extreme of circumstances (e.g., Boin et al., 2016, p. 85).

Thirdly, the analysis of formal modes of public participation highlights the prevalence of Finnish corporatism, where labour market organisations have an intimate relationship with the public authorities (Koskimaa et al., 2021). Most organisations that participated in drafting the emergency measures and policies during the pandemic were labour market organisations or other well-established civil society actors. This finding indicates that, from the perspective of the public authorities, the issues of economic recovery tend to surpass other issues related to a variety of long-term societal, moral, and ethical concerns. The attention to quick economic recovery may explain why the long-term impact of the emergency measures on the welfare of young people, for example, was not anticipated.

Finally, due to the lack of critical voices in public arenas, some groups emerged in Finland throughout the pandemic who contested government measures. These groups engaged in informal counter-democracy practices, such as information campaigns, protests, and demonstrations. Contestatory forms of public participation allowed citizens to scrutinise and to challenge public policies by illuminating the injustices and inequalities created by these policies. For example, in an attempt to draw attention to the impact of the coronavirus restrictions on the cultural sector, the cultural workers organised large-scale demonstrations. In this manner, these groups could address the concerns of the unorganised workers and not only the demands of the most organised and privileged groups. The research shows that the activists impacted pandemic measures and policies to some extent (Vuorelma & Lehtonen, 2024).

Social media platforms are often utilized by activists as a tool to implement modes of counter-democracy to challenge public authority. Social media allow activists independence from mainstream media platforms by providing them with the means to make their concerns public and also to recruit new members. In the face of multiple voices on different platforms, controlling media space during emergencies and sharing information with citizens becomes a difficult task for authorities. Moreover, social media also allow misinformation to spread more easily among the public, which can undermine the chosen emergency measures and policies. In response to this challenge, authorities may try to control media space by shutting down harmful social media accounts or discredit the activists by publicly undermining their credibility (Mäkinen, 2023). Through

these strategies, the authorities attempt to delegitimise the activists and downplay their impact on public opinion on the emergency response.

Seeking alternative means to connect forms of counter-democracy to the arenas of public policymaking could serve as a more constructive way to react to activists' and other social groups' demands. The coupling of formal with informal participation could lead to more encompassing "ecologies of public participation," where diverse forms of participation can function as a part of a wider system (Chilvers et al., 2018). The first step in this direction would be for public authorities to recognise the value of the "untamed force" of activism that can emerge outside formal participatory processes. Even if activists obdurately hold onto the positions they should reasonably give up, they may benefit collective decision-making by demanding that authorities provide better justifications for their decisions (Moore, 2017, p. 181). A more transparent and inclusive democratic system would create the opportunity for citizens to scrutinise and to challenge public policies, while public authorities would be required to respond to citizens' concerns and justify their decisions to the wider public.

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### Conflict of Interests

The author declares no conflict of interest.

### Data Availability

The written statements issued in public hearings of parliamentary committees are available from the official website of the Finnish parliament: <https://www.eduskunta.fi/EN/Pages/default.aspx>

The statements on governmental acts are available in the government-sponsored crowdsourcing platform Lausuntopalvelu (only in Finnish or Swedish): <https://www.lausuntopalvelu.fi/FI>

The citizens' initiatives are available on the government-sponsored website Kansalaisaloite (only in Finnish or Swedish): <https://www.kansalaisaloite.fi/fi>

The data from the Citizens' Pulse survey have been archived at the Finnish Social Science Data Archive from the beginning of 2021 onwards: <https://services.fsd.tuni.fi/catalogue/series/86?lang=en>

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### About the Author



**Mikko Värtö** is a postdoctoral researcher in political science at Tampere University. He is currently working on a project that studies the institutionalisation of democratic innovations. His research interests include democracy theory, democratic innovations, and public participation. He is particularly interested in studying the potential roles of deliberative mini-publics in crisis management.

# The Body as a Tool for Demanding Climate Action and Justice

Margaret Tilk <sup>1</sup> , Antje Jacobs <sup>2,3</sup> , and Karin Hannes <sup>2</sup> 

<sup>1</sup> Independent Researcher, Estonia

<sup>2</sup> Research Group TRANSFORM's Idiosyncratic Inventors Collective, KU Leuven, Belgium

<sup>3</sup> Social Transformation and Education Academic Group, University of Melbourne, Australia

**Correspondence:** Antje Jacobs ([antje.jacobs@kuleuven.be](mailto:antje.jacobs@kuleuven.be))

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## Abstract

The escalating frequency and intensity of natural disasters underscore the urgency of the climate crisis. Against this backdrop, the global climate movement has surged, amplifying awareness of the climate emergency and pressuring governments and corporations to take decisive climate action. In climate manifestations, activists are increasingly using their entire body for/in climate activism, with Extinction Rebellion activists barricading driveways, and Just Stop Oil and Greenpeace activists gluing or tying their bodies to objects. These bodily ways of participating in climate activism have provoked public and political hostility, with concerns being raised about these so-called “radical” forms of bodily activism. In response to these growing hostilities towards bodily climate activism, this study maps how the body is intimately connected to other actors when performing activism. We conducted interviews with nine European climate activists and, based on their stories, we mapped themes of relational practice of bodily activism. Our findings suggest that the body as a tool for climate activism manifestations is in relation to other material agencies, including (a) the public space, (b) other climate activists, (c) material objects, (d) law enforcement, (e) the general public and media, and (f) climate governance and policy. The body is not a stable and autonomous figure, but a dynamic and ever-changing political tool through its socio-spatial configurations that co-constitute climate activism, making the role of the individual body in climate change activism manifestations elusive. Through its relational transformative collectivity, bodily climate activism proves itself as a valuable form of non-violent participation in politics.

## Keywords

bodily activism; climate activism; climate change; embodiment; public participation; social constructivism

## 1. Introduction

In the last decades, climate crisis has become more discernible due to the increase in natural disasters such as California wildfires and Hurricane Harvey in the USA, floods in Rwanda and DR Congo, Millennium Drought and bushfires in Australia, and heatwaves all over Europe (Braun, 2023; Bureau of Meteorology, 2015; California Department of Forestry and Fire Protection, 2025; “Death toll from eastern DR Congo floods,” 2023; Fitzpatrick & Spialek, 2020; Tondo, 2023). The risks of these climate disasters disproportionately affect people living in the Global South, while countries in the Global North bear more responsibility for climate change (Auer Frege et al., 2023; McKenzie et al., 2023). Relating to the escalating frequency of climate disasters and its related injustices, the climate movement has gained momentum globally. Mobilized by a shared concern for the climate crisis, the public increasingly participates in collective actions and manifestations, raising awareness about the climate emergency, and pressuring governments and companies to take climate action. Here, we approach climate activism as a participatory practice that is both shaped by and responsive to matters of climate crisis (Amelung & Machado, 2019).

In advocating for climate action and justice, activism as a form of public and political participation has manifested in an array of ways, from organizing global marches, suing companies and governments for failing to shield the citizens from climate dangers (Di Sario, 2024), to publishing articles on online fora, creating and sharing videos on TikTok about sustainable living, and so on. Increasingly, activists are using their entire body for/in climate activism, with Extinction Rebellion activists barricading driveways, Just Stop Oil and Greenpeace activists gluing or tying their body to objects, Movimento dos Trabalhadores Rurais Sem Terra (The Landless Workers’ Movement) activists occupying Brazilian latifundia, and activists of Fridays for Future sitting outside in harsh weather conditions. However, the role of the body in climate activism and the tactics of using the body as a tool in public spaces are poorly understood (Hohle, 2010). In the last decades, the interest of research has shifted from physical public space to virtual public space (e.g., Eileraas Karakuş, 2020; Ferreday, 2017; Hynnä & Kyrölä, 2019; Johansson, 2021). The internet has surely changed the nature of physical demonstrations as there is now a new emphasis on catching the attention of social and traditional media (e.g., the Black Lives Matter movement using social media in “Blackout Tuesday” to protest against police brutality and racism, or globally shared videos on TikTok on climate change and climate injustices).

While activism in online spaces has grown in intensity and significance, the censorship of social media platforms such as the governmentally-induced internet shutdowns in the Islamic Republic of Iran after the death of Mahsa Amini in 2022 led to growing physical protests across various Iranian cities, exemplifying the necessity for physical demonstrations. Butler (2015) stresses that in order to apprehend the effect and power of activist manifestations, we need to reflect on the bodily dimensions of activism and look at what the bodies require and what they can do. Although the body in activism in the public space has been researched before, there seems to be a lack of consideration of cases where the body is a tool for activism fighting against the exploitation of natural territories. Here, the body can be conceptualized as an essential geographic reference for human beings that contains not only a memory of the past but also a desire for the future that it shares with meaningful others. Several studies have investigated the role of bodies in the public space in relation to social movements. Notable examples are Foellmer’s (2024) work on climate organization Letzte Generation’s (Last Generation) civil disobedience actions as communal choreographies, where seemingly passive bodies pro-actively stop traffic flows in road blockages, the work of Eileraas Karakuş (2020) and Kraidy (2012) about the use of the body as a medium in the Arab Spring, Karakaş’ (2018)

work on dissident communities' relational encounters with bodily dimensions, as well as Alaimo's (2010) work on the nude body and its mutual vulnerabilities with human/animal/environment. In addition, the intertwines of the affect and embodiment in activism manifestations have been researched, for example, by Protevi (2009, 2011). In his exploration of "political physiology," Protevi examines how bodies, minds, and social settings are intertwined. His work highlights how politically induced emotions in activist movements can bypass subjectivity, generating somatic and social connections. Further, Rousell et al. (2024) have studied affect and activism in their work on young climate justice activists' participation in politics in "dynamic affective relationalities that re-orient and re-organize social life" (p. 1294), which goes beyond the usual approach of advocating for demands from the state. Perugorría and Tejerina (2013), in turn, have been focusing on cognitive, emotional, and relational processes in identity-synchronization that allowed people from different backgrounds and worldviews to feel part of the "15M movement." However, the role of the body in public manifestations, its relations with some of society's most powerful structures, and how this affects the body has to be further explored.

The empirical question of how climate activists use their body in a particular territorial context is important to examine in the current atmosphere of growing hostility towards climate activist manifestations, where the public and politicians have engaged in a discourse about "good" and "acceptable" activists versus "bad," "terrorist," and "radicalized" activists. This is particularly related to bodily ways of performing activism in the public space. During the spring of 2023, newspapers from all around Europe captured this tension, reflecting negatively on climate change activism and merely focusing on how activists use their bodies during manifestations in the public space. According to *The Times*, French conservative newspaper *Le Figaro's* research shows that 73% of the French population thinks the authorities should treat climate activists as terrorists (Chazan, 2023). Additionally, the French environmental platform Les Soulèvements de la Terre was almost shut down by the then Minister of Interior Gérald Darmanin because the police claimed the activists of the platform were inciting violence, and thus faced direct hostility from governmental institutes (Chazan, 2023; "La dissolution du collectif," 2023). In Germany, the newspaper *Der Spiegel* published Economy Minister Robert Habeck's claims that protecting the climate is the whole society's responsibility and that radical activists like the German Letzte Generation harm this shared concern ("Habeck kritisiert neue Klimaproteste," 2023) while a few months later the cover of the paper stated in German "The new public enemies. Letzte Generation: About the inner life of a radical movement" ("Die neuen Staatsfeinde," 2023, our translation). These articles showcase how only a limited range of activist practices is deemed acceptable by the media and certain ways of bodily activism are met with hostility.

During her fieldwork on the protests of Letzte Generation as choreographic interruptions, dance and theatre scholar Susanne Foellmer experienced this hostility also on the ground, as she observed activists using their bodies as roadblocks, which triggered the passersby to use violent language towards the activists, such as stating that they wish to have them violently killed (Foellmer, 2024). These public discourses reflect the growing hostility towards bodily ways of participating in climate activism. The bodily actions of activists often make them the focal point of public and media scrutiny, which contributes to the hostility. However, what often has been left unnoticed is the non-violent character of these bodily actions. Butler (2015) claims that the media has great responsibility to showcase the nonviolence of activists' civil disobedience action: "Such demonstration is not easy to do when there are those who can only read the tactic as hatred and the continuation of war by other means" (p. 192).



In response to this growing concern of the public towards bodily activism, we explore the bodily participation practices climate activists engage in amidst growing hostility towards such activism manifestations. More specifically, this study *maps how the body acts as a tool for climate activism, and how such engagements create meaning*. We study these dynamics within a European context, because public climate activism manifestations are legal and allowed in this region, while activism in other regions and situations might face direct hostilities where authoritarian institutes control and demobilize activist manifestations (e.g., across Latin America where environmental activists are being sued and arrested; Carrere & Romo, 2021). Through interviews with climate activists, we aim to acquire insights into bodily activism practices that are deemed “radicalized” in the media (Chazan, 2023; “Die neuen Staatsfeinde,” 2023). We further aim to offer a theoretical framework to analyze bodily performative manifestations in the context of climate activism in the public space.

## 2. Theoretical Framing: The Body as a Tool

The role and potential of the body in public manifestation is a critical area of inquiry, particularly in connection to various power structures. How these structures affect the body and its use in activism warrants further exploration. In this exploration, we draw on social constructivism articulated by Berger and Luckmann (2018) to conceptualize the “body as a tool” in climate activism manifestations. Social constructivism argues that reality is constructed through social interactions and that the body plays a crucial role in these processes. In conceptualizing the body as a tool, the eccentric relationship between the self and the physical body is central to the theory (Berger & Luckmann, 2018). As an individual develops, learns, and creates in the social world, their eccentric connection to their body plays a central role in their lived experience, with the body being both an integral, biological part of the person and something they possess, a medium; a person is the body, but at the same time, a person also owns the body (Berger & Luckmann, 2018). Understanding the self involves searching for a balance between having a body and being a body, affecting how one behaves and participates in meaning-making practices (Berger & Luckmann, 2018). The feeling of having or owning a body implies that one does not identify solely with their body, but sees the body as an entity of being possible to rule (Berger & Luckmann, 2018). In this state, the body can be treated as an object or a tool, which emerges through specific practices. This can be used strategically, for example, to better express one’s political opinion in street activism, rallies, or political art.

## 3. Methodology

We studied the body as a tool in climate activism through a qualitative research design consisting of semi-structured interviews. We analyzed the stories shared by interviewed activists by mapping themes of relational practices of bodily climate activism through the concepts of relations, affects, and capacities (Fox & Alldred, 2021).

### 3.1. Data Collection: Interviews

Berger and Luckmann (2018) regard language as the main means by which logic is attributed to the social sphere and forms the foundation for legitimation. With this in mind, we conducted interviews with nine climate activists from various regions across Europe. Here, interviewees did not take on a privileged role within a socially constructed setting. Rather, interviewees were considered key informants providing insider knowledge about a certain setting, in this case, climate activist manifestations in Europe between 2020 and



2022. Interview topics related to the interviewee's experience with climate activism, specifically relating to public space, the body as a tool, relationality to other people in the manifestations, and personal experiences with climate change. Example questions that were asked were: Where have you performed climate activism? What are the reasons you engage in activism in the offline public space and not (only) online? If you have acted violently during a manifestation, then what led you to this approach of activism? How do you and your body influence political discussion about the climate crisis?

The participants (see Table 1) were found by contacting the communication personnel of different climate activist organizations, posting adverts in Telegram and WhatsApp groups of activist organizations, and through writing personal messages to people close to activist circles, followed by snowballing. The interviews were conducted through the video conferencing software Zoom in April and May 2023, sometimes encountering problems with internet connections, which affected the flow and openness of the interviews. In addition, the conversations took place in English, while none of the interviewees and researchers were native speakers of the language. We have used pseudonyms to anonymize the interviewees for their personal safety.

**Table 1.** Overview of the selected interviewees.

Pseudonym	Age	Gender	Country where the activism was performed	Climate activism organizations
Annika	24	Female	Estonia	Fridays for Future, Estonian Greens
Bruno	32	Male	Belgium	Extinction Rebellion
Carmen	20	Female	Portugal	Fridays for Future
Damiano	44	Male	Italy	ASud, Ultima Generazione, Extinction Rebellion
Emmi	36	Female	Finland	Greenpeace Nordic
Ferdinando	53	Male	Italy	Extinction Rebellion
Gabriel	44	Male	France	Extinction Rebellion, Fridays for Future
Hans	24	Male	Germany	Ende Gelände, Die Falken, Antifa
Ingel	24	Female	Estonia	Fridays for Future

The interviewees were part of nine different climate organizations that approach climate manifestations in the public space in their own way. The two most common organizations in this study, Fridays for Future and Extinction Rebellion, are known for shifting the focus of climate activism more strongly on state actors, rather than on non-state actors (de Moor et al., 2020). While the activist part of Fridays for Future often engage in standing at a square in assembly, holding signs, listening to speeches, and chanting in unison, Extinction Rebellion activists lean more towards civil disobedience in the form of using bodies as roadblocks, disrupting events and meetings, playing dead on the road, locking body parts to cars and fences, occupying spaces, and in more extreme cases, breaking property. The other organizations mentioned in Table 1 mainly use civil disobedience as their form of climate activism manifestation, except for the Estonian Greens, which participates in peaceful demonstrations usually together with other climate organizations.

### 3.2. Analysis: Mapping Themes of Relational Practice of Bodily Activism

The analysis of the interviews focused on mapping themes of relational practices of bodily activism, seeking to deepen our understanding of how the body serves as a tool in climate activism. From Fox and Alldred's ethological toolkit (2021) we borrowed three concepts—relations, affects, capacities—that corresponded

with our analytical focus on the relational practice of climate activism in a specific material and cultural environment. These concepts—relations, affects, capacities—are key meaning-making components in/of climate manifestations, found in the stories of the interviewees. They focus primarily on the interactions between various humans (e.g., activists, passers-by, law enforcement), places and spaces (e.g., public squares, driveways), and material and cultural environments (e.g., urban infrastructures, regulations). Themes stemming from these concepts can be human and non-human *relations* during climate manifestations, as well as *affects* and emerging *capacities* that (re)produce climate activism. These relations, which have the ability to affect or be affected in varied capacities, shape how the body is constructed as a tool during climate manifestations. It is crucial to note, however, that such mappings are manifold and dynamic: Our approach led us to generate only one of ample possible mappings of the body as a tool advocating for climate action and justice.

## 4. Findings: The Relational Practice of Bodily Activism

To understand the body as a tool in climate activism, we mapped various relations: the body as a tool for climate activism in relation to public spaces, to other climate activists, to material objects, to law enforcement, to the general public and media, and to climate governance and policy. Within these relations, we explored how affects and capacities are formed in and are forming these relations.

### 4.1. *The Body as a Tool for Climate Activism in Relation to Public Spaces*

When discussing activism approaches such as stationary activism (i.e., holding signs, listening to speeches, shouting, and chanting) and more active forms of activism (i.e., performing civil disobedience by using the body as roadblocks, sitting in front of driveways, and locking body parts to cars and fences), the body relates to space in order to participate in shifting public opinion (to affect psychologically and socially) and changing policies (to affect socially and economically). The public spaces not only enable the climate activism manifestations to happen and aid climate-related communication, but the manifestations also change the very capacities of the public spaces. This might be done by staying in one space for prolonged times or marching around the city. The interviewees described using the latter method when there did not exist a meaningful public space, such as a square in front of the town hall, and thus the streets themselves must be politicized through walking in assembly. A good example of the former came from Ingel, who explained how the parking lot, in front of the house of the parliament in Tallinn, Estonia, transformed through a gathering of people into a perfect place for demonstrations:

There's a big space, it's almost like it's made for protests because it is like right in front of the building there. It should actually, if you think of city planning, there should be like a park or a nicer area there. There shouldn't be a car park right in front of the main parliament building. But that's how it is and at least it leaves space for protests. (Ingel, interview, 28 April 2023)

More obvious ways of accommodating a space, to make it more suitable for a manifestation, is by creating new living arrangements and communities inside the action, such as the creation of care-units or even play areas for children: "You have a community for those days. For those hours. Kids are taking it. There is a playground for the kids. It wasn't [there], the government didn't put a playground for the kids in. We did" (Bruno, interview, 3 May 2023). In the extract, Bruno described a week-long occupation of a place of power

in Paris, during which he and other climate activists created an alternative system of living and managing daily activities by birthing a new “law enforcement” (which included designating individuals to regularly check in with newcomers, rotating responsibilities for policing both the police and other activities), childcare (e.g., building a temporary playground), and sleeping and living arrangements (e.g., bringing haystacks and hammocks for sleeping, portable toilets and kitchen utilities for taking care of the bodies, and organizing workshops to pass the time). This results in a diffraction of the usual relations between the activists’ bodies and the space, forming new affects and widening the capacities of the assembly.

#### 4.2. *The Body as a Tool for Climate Activism in Relation to Other Climate Activists*

Across different civil disobedience climate manifestations, the large assembly of bodies is divided into smaller unnoticeable assemblies of 5 to 12 people, which are usually called affinity groups, that take care of each other and operate as a unit (Ferdinando, interview, 28 April 2023; Hans, interview, 19 April 2023). Hans described the importance of performing activism in a group and not alone: “It’s important because that’s your safety net. You trust those people. You see those people almost on a daily basis, and you fall back on them and it makes you feel safe” (Hans, interview, 19 April 2023). These affinity groups thus serve as networks of care and additional support amidst hostility, which fosters a strong sense of belonging and life force, helping with individual experiences of anxiety relating to climate change and/or manifestations. The focus of the activists shifts from an individual account of climate-related challenges to the shared cause. The feeling of belonging in the affinity groups and the climate activism organizations is either friendship-like or based on common agreement to fulfill a task. Inside this activist community, there exists a strong sense of “we,” a mark of relations full of affect. This was directly reflected in the ways the interviewees told their stories during the interview: They often answered questions about their experience with stories about the common experience in their organization. While the common experience was highlighted, interviewees also emphasized the variety of lived experiences of activism and how there exists solidarity towards individual precarious situations of peers, for example due to their family situation or physical health. Bruno, for instance, explained that his female acquaintance experienced a huge trauma as she did not know the police would strip search her (Bruno, interview, 3 May 2023).

While gathering in the public space, verbal actions occur as a crucial tool for creating affects in the assembly. Verbal bodily actions like chanting a slogan or singing in unison functions, according to Annika and Ingel, as a way to keep up the spirit of the participants and get the message across (Annika, interview, 20 April 2023; Ingel, interview, 28 April 2023):

Singing is also something...that unites people....It’s kind of similar to chanting, but singing somehow is maybe calmer, it’s not so angry. [It] kind of tries to get the message through in a softer way. And it’s even more, [in] that it’s something meant for us, it’s not meant for others. You know, chanting we want the others to hear it, but singing is more like for our own group. (Annika, interview, 20 April 2023)

Besides establishing such a sense of belonging, the activists also described having a strong sense of *life force* which is experienced as a therapeutic, healing or fueling of the body with energy and adrenaline, aggregating the activists’ capacities as a group. Here, life force refers to a strong feeling of vitality or feeling that one is living their life in the moment and to the fullest extent. For some, it helps with their own mental health struggles. For others, this ensures the creation of a safer space among fellow activists: “I went through depression with

[the help of] Extinction Rebellion, and it was really helpful. Also, regenerative culture [a collective form of after-manifestation self-care] was...very hype [exciting]" (Bruno, interview, 3 May 2023). The aforementioned ways of relating to others with affect relieve mental health struggles and feelings such as ecoanxiety which preceded joining the movement. Climate activist manifestations are not only a place for supporting climate policies, but become a place for interpersonal relationships as well.

#### ***4.3. The Body as a Tool for Climate Activism in Relation to Law Enforcement***

One of the groups of humans that activists' bodies are closely related to is law enforcement. The police, for instance, is either seen as a potential protector of activists (law enforcement as an enabler of capacities) or as a hostile power institution which activists protect themselves from (law enforcement as a constraint of capacities). Here, the previous police encounters and individual experiences shape the expectancy of law enforcement interactions. While Emmi expressed feeling surprised when the police arrested her during the civil disobedience action in Finland, Bruno, who grew up in Iran, was surprised the Belgian police did not strike and pound him during a stationary form of activism and "just" arrested him (Bruno, interview, 3 May 2023; Emmi, interview, 6 April 2023). This situatedness is closely connected to the imagined threat, and co-determines activists' preparations beforehand for protecting themselves and others based on certain perspectives and expectations on how the police could act.

While the more passive activists performing stationary forms of activism typically did not describe prior preparations for protection against law enforcement, those involved in civil disobedience activities take extensive measures to protect their bodies from potential hostility in police interactions. They rely on support from their affinity groups, in which they choose a person whose function is to calm down the situation by talking with the parties involved, express care during and after the action, and use their bodies to form physical shields to protect the most vulnerable ones (Bruno, interview, 3 May 2023; Damiano, interview, 8 May 2023; Gabriel, interview, 10 May 2023; Hans, interview, 19 April 2023). Ahead of a manifestation, potential physical and mental struggles are discussed. For example, Bruno described how he was advised not to participate in certain kinds of action to ensure he would not lose his residence permit, and Hans explained how in his affinity group, there was a person with asthma whose body was first in the line to being protected by the group (Bruno, interview, 3 May 2023; Hans, interview, 19 April 2023). In their relations with law enforcement, the activists also use playfulness and creativity as tools for protection. Many of the interviewees extensively talked and reflected on their playful interactions with the police or on their attempts to look for holes in the police system, for example, by building tree houses to avoid the trees from being cut down, as law enforcement was prohibited from climbing the trees or cutting down those with people in them, or playing football in the police cell among the activists or with the police in order to turn the repressive situation into a playful one (Damiano, interview, 8 May 2023; Hans, interview, 19 April 2023).

#### ***4.4. The Body as a Tool for Climate Activism in Relation to the General Public and the Media***

Besides law enforcement, activists are related to the general public and the media through reliance on their bodies, especially in the context of more "disobedient" forms of activism sparking irritations and hostility towards activists for blocking the passers-by's and car drivers' way. Gabriel described: "I would have people just yelling at me, insulting me from time to time" (Gabriel, interview, 10 May 2023). However, at the same time, the passers-by and the media serve as protectors of the activists as they witness or document everything that

is taking place on the streets. The existence of media on the streets was described as something that brings a sense of safety to the activist manifestations as they are policing the police: “The more visible we are, the more I’m relaxed that the police is not gonna offhand. I was always looking for cameras. I was always looking for bystanders, for normal people looking out” (Bruno, interview, 3 May 2023).

In the context of contacts with the media, the body serves as a tool for physically representing feelings, ideals, and arguments of the movement to the general public with the objective of affecting them and bringing them closer to the cause. The interviewees particularly mentioned how they consciously used their body to show despair:

When you are on your knees, you are sending a completely different message than when you are just sitting down. And for people who are angry, when you are just sitting, you are like the asshole who is blocking their day. But when you are on your knees, you’re fragile. So, you are sending a completely different message just by the position that you have. (Gabriel, interview, 10 May 2023)

By putting his body in an uncomfortable position in which he could not protect himself from the blows and pushes, he sent a message of desperation and sacrifice. This physical and thus emotional representation of the cause, which engaged the audience on the level of emotions, was described as one of the important reasons for performing activism offline and not only online, as this type of physical engagement and affective relation was not possible online.

The media further functions as a vehicle activists use to louden their voice. The articles, posts, pictures, and videos in the media enhance the capacities of the body as a tool to change politicians’ understanding of public opinion. The face and its expressiveness were seen as especially important mediums by Carmen as she explained that emotionally loaded pictures travel faster in social media (Carmen, interview, 1 May 2023). With the help of these emotionally loaded videos and pictures, the message of the cause has spread around the world, creating a shared understanding of the climate crisis. Furthermore, the number of people that attend the manifestations and their expressiveness are important, as all of those have an effect on how newsworthy the gathering is regarded.

#### **4.5. The Body as a Tool for Climate Activism in Relation to Material Objects**

Material objects used in climate manifestations also play an important role as these are related to activists’ bodies and with the aforementioned humans, places, and spaces, and with establishing units of care among peers. For example, Hans described taking food and water for at least two people. He carried extra water bottles to wash out tear gas from the eyes and umbrellas to protect activists from the blows of police (Hans, interview, 19 April 2023). Other instances of using material objects in climate manifestations are gluing one’s body to a car, using makeup and costumes, and using performative or symbolic objects, e.g., a replica of the DeLorean time machine from the movie *Back to the Future* (Bruno, interview, 3 May 2023; Damiano, interview, 8 May 2023).

According to the interviewees, the usage of facemasks during the Covid-19 pandemic affected how the body could be employed as an emotional representation of the feelings of the masses. The mandatory facemasks and other caution measures impacted encounters with law enforcement and passers-by: “Masks,

to be honest, I don't like it much but I think the reaction of people to activists with masks can be more aggressive" (Gabriel, interview, 10 May 2023). Masks covered the activists' faces, which they regarded as one of the most important areas of the body for influencing the audience. Not only are the emotions hidden, but the element of being there on the square or street fully identifiable is lost. Consequently, activists' capacities to affect are constrained when wearing a mask.

#### **4.6. *The Body as a Tool for Climate Activism in Relation to Climate Governance and Policy***

Expanding upon previous sections, activists have increasingly utilized their collective bodily presence in public spaces to challenge and reshape climate governance. This approach stems from a widespread perception that existing policies and institutions are either unwilling or incapable of effectively addressing the climate emergency. As argued by Emmi from Finland:

It is just [by] the sum of the bodies of people gathered that it looks like there are many people who care....I think it is important to create pressure on the decision makers that there are people who care and who come to the street to demand action. (Emmi, interview, 6 April 2023)

The bodies as a matter taking physical space have a socio-spatial impact by changing the narrative of climate matter being a niche subject, thus affecting the material reality of climate change. Moreover, by gathering in assembly, the individuals who lack political power—for instance, not having the right to vote or influence the political discussion through their work—gain political legitimacy and aggregation of capacities. This is especially the case in the weekly gatherings of Fridays for Future, as the schoolchildren can be seen as pre-political or extra-political subjects who belong to the private sphere and are not carriers of the popular will (Butler, 2015). Twenty-year-old Portuguese Fridays for Future participant Carmen described her feelings relating to the impact of her actions which took place a few years earlier:

They [a new Portuguese political party focused on environmental issues] brought to the parliament issues, environmental issues. So, they could say, for example, like, see those kids outside protesting, we need to hear them. And they actually did. Like they were passing laws. (Carmen, interview, 1 May 2023)

The importance of bodies on the streets for climate governance was especially felt during the Covid-19 pandemic when the bodies could not gather, which affected the capacities of the assembly. The pattern of the number of participants in the climate activism movement diminishing was mentioned in various interviews, attributing it to there not being any physical personal meetings in addition to the media's and politicians' focus shifting from new climate policies to solely focusing on topics related to the Covid-19 pandemic. After the pandemic, the number of activists and the interest of politicians in new climate policies did not return to the same level.

### **5. Discussion: The Body as a Political Tool**

We initiated this study process to acquire insights into the practices in climate activism and to offer a theoretical framework to analyze bodily performative manifestations in the context of climate activism in the public space. Here, we engaged with climate activism as a participatory, relational and political practice that is mobilized by shared matters of concern. Within this practice, we approached the body not as a stable

and autonomous figure, but as a dynamic and ever-changing tool through its socio-spatial configurations that co-constitute climate activism, making the role of the individual body in climate change activism manifestations elusive. Therefore, we argue that the body as a tool negotiates the political regimes of climate change through its relation to other agencies including (a) the public space, (b) other climate activists, (c) material objects, (d) law enforcement, (e) the general public and media, and (f) climate governance and policy, through which the body is being constructed as a political tool.

The climate activists found in the movement great feelings of belonging, which emphasized the strong bond of relationality among the activists and their surroundings. The activists defined their bodies through collective relational and affective terms, for example by being part of a mass, a cell of a community, or a protector of others. The terms elucidate the simultaneous existence of a body as a tool and the assembly of bodies as a tool which are in relation with other humans, material environments, and objects. The sense of belonging and its blooming life force enlarging the capacities of the group among a heterogeneous population was one of the central outcomes of the action and something that was born out of the aggregating power of affective flows in the gathering of people. In their work on the topic of assembling masses within the physical public space, other scholars have highlighted that social media has an important aggregating power as a tool of emotional narration as it constructs an affective sense of togetherness among heterogeneous participants (Gerbaudo, 2012; Juris, 2012). However, our analysis shows that while social media is an effective tool for gathering different people and spreading the message, the relief from climate anxiety and loneliness is found in the community on the ground.

In addition to the body as a tool being sustained by other bodies and the public space, the activists were accompanied by the police and the media, both being simultaneously the enablers and constrainers of the capacities of the action. Law enforcement was repeatedly mentioned as the main threat during climate activism manifestations, with hostility from the police often perceived as a significant risk. Nevertheless, the simultaneous sense of safety created by the presence of law enforcement enabled the activists to continue their actions. In a complex way, the activists protested against the state, while law enforcement simultaneously protected the activists and acted as a source of hostility leading the activists to protect their bodies from the police. As such, the activists and law enforcement navigated through and tried to balance hostility and protection. This “dance” of power dynamics has been conceptualized as “communal choreographies,” where in road blockage actions the bodies of the activists stopped the movement of the traffic, while the law enforcement enacted their own choreography by directing the movement of protesters (Foellmer, 2024). Through the directing of the bodies of the activists, law enforcement restored the standard urban rhythms that the bodies of the activists had disrupted (Foellmer, 2024). At the same time, our analysis sheds light on how diffracting the standard urban rhythms with the bodies is a tool to catch the attention of the media.

The activists used the presence of the media as one of the ways to protect their bodies from the police. In addition to having the capacity to protect, the media has the power to change a local incident into a politically potent one (Butler, 2015). The press does not function only as a reporting tool but is a vital part of the activist manifestation as it “constitutes the scene in a time and place that includes and exceeds its local instantiation” (Butler, 2015, p. 91). As both law enforcement and activists are aware of this socio-spatial configuration, they change their behavior based on the presence of cameras. Here the experiences of activists differed greatly based on their situatedness as there existed great differences in the normative



action of the police, the level of power of the media, and how the latter assesses the former's actions. These are not static relations, as *Cuerpo-Territorio*—a Latin American decolonial, Indigenous community and feminist epistemology—has demonstrated by regarding the body as the first territory one occupies, thus being an active site of struggle against capitalist, patriarchal, and colonial logics of extraction, exploitation, and dispossession, that impose violence on marginalized people's bodies and the land (Cabnal, 2010; Schmidt, 2024; Zaragocin & Caretta, 2020). Here, the dynamic and relational nature of the body as a tool, which was reflected on in our analysis, comes forward.

Within this activist–police–media configuration, material objects such as Covid masks co-constructed the actions of activists during manifestations. Constraining the capacities of the body as a tool, the mask hindered activists from showing their emotionally loaded, identifiably face to the media, which generated different affects: Not only were they deliberately identifiable to the police and through this materialized the extent of the sacrifice they were willing to make for the climate, but they were also showing their most vulnerable feelings to the wider public in order to affect the passers-by, both on the street and online. As the interviewees narrated, and Gerbaudo (2012) has written, these “spontaneous” emotional moments seen online can sometimes take place due to thorough previous organizational work by a nucleus of organizers of the manifestation.

The climate activists define their bodies through collective terms. Through this understanding of “bodies” rather than individual “body,” they highlight the relations between the bodies, the physical conditions of climate change, and the streets as the place of protests. Although some of the civil disobedience actions can seem violent and unpredictable for the viewer looking at them from the outside, inside this action there exist networks of care and solidarity. Still, in the public space there exist various potentially hostile institutions of power which the activists' bodies are in relation with, for example the law enforcement and the media. Interestingly, the activists use the latter to protect themselves from the former and use the help of the former to sustain their activist manifestation. In the context of the climate crisis activist manifestations, the body is being constructed as political in its relations to other bodies and other matter.

Hostilities to bodily climate activism, rooted in the belief that it is radical, diminish the legitimacy of activists' responses to the climate emergency. However, drawing on our results, we argue that bodily climate activism is a valuable avenue for non-violent public participation because of its relational transformative collectivity. This collective and relational approach creates opportunities for politicizing topics normally seen as non-political and transforms the discourse on climate change from an abstract natural science dilemma to a clear socio-economic problem. In the socio-spatial configurations that shape bodily climate activism, the body is a dynamic, ever-changing, and relational political tool, which goes beyond our usual understanding of the body as a stable and autonomous figure performing individual actions. This relational transformative collectivity holds particular significance in the European context, as the willingness of an assembly of bodies to risk arrest or harassment challenges the existing rationalities and core values of European countries. This tension is reflected in the responses of the politicians and the media.

Collective bodily public participation questions “the inchoate and powerful dimensions of reigning notions of the political” (Butler, 2015, p. 9). The activists are pushing the climate issue to be a political and material issue, emphasizing the role of public spaces. The stories of the interviewees demonstrate that these spaces enable emotional encounters, which are crucial for their cause, as the affective relational encounters

emphasize the bodily dimensions of the climate crisis. Unlike LGBTQIA+ activism or healthcare issues, climate politics is not commonly seen as an issue of the body. Bringing the bodily dimensions forward outlines how the climate protests are not only about abstract challenges related to global warming—they are also about concrete socio-economic circumstances such as access to food, decent living conditions, having or not having children in the future, mass migration of climate refugees, and systemic inequality (e.g., in access to resources, or in the toxicity to which some bodies are more exposed than others). In this manner, bodily climate activism can be taken as an exemplifier of Butler's (2015) understanding of sustaining the body by being at the forefront of future activism manifestations.

## 6. Conclusion

In their work on assemblies as plural forms of performative action, Butler (2015) discusses the role of the physical body in activism:

It matters when public squares are filled to the brim, when people eat and sleep there, sing and refuse to cede the space, as we saw in the gatherings in Tahrir Square, and continue to see in other parts of the world. (p. 94)

Due to the growing and dynamic impacts of the climate crisis (e.g., shifting ecosystems, frequent and severe weather events, rising sea levels, as well as increased poverty, climate migration, etc.), activists gather in public spaces concerned about livable futures on this planet. During such gatherings, the activist's body becomes a participatory public tool, advocating for change in environmental policy regulation, and demanding responsibility and urgent change in climate policy. Here, the activist's body is not a stable and autonomous figure participating in climate activism manifestations. Rather, the body and its participatory practices (e.g., barricading the driveway, sitting on public squares, tying their body to objects, etc.) are part of socio-spatial configurations of the climate activism manifestation itself, which include (but are not limited to) the public space in which they operate, other bodies, law enforcement, etc.

As recent media articles reflect increasing hostility towards bodily ways of performing activism, often labeling them as "bad" or "radicalized" (Chazan, 2023; "Die neuen Staatsfeinde," 2023; "Habeck kritisiert neue Klimaproteste," 2023), our study provides insights into how such bodily ways of performing activism come into being and make meaning. Further, we challenge the notion that bodily activism is a violent and illegitimate way to participate in politics. Instead, we regard it as a valuable non-violent form of public participation through its relational transformative collectivity, which has the ability to redefine what matters are regarded as political. As they advocate for climate action and climate justice, we suggest so-called "radicalized" forms of activism are established in relation to surroundings and practices. In other words, the bodily ways of performing activism are in constant conversation with hostilities practiced by the media and law enforcement. Such hostilities and bodily activism mutually constitute each other: The activists engage with these hostilities in relational ways as they use the media to protect from law enforcement and use the help of the police to sustain their activist manifestation, while the attention they receive from the media is one of the main reasons why the activists gather in the public space. In these interactions, the body becomes a dynamic tool to negotiate the political regimes of climate change through being in socio-spatial configurations with other humans, material objects, and environments. This is prevalent in the context of bodily climate activism in the public space in Europe, as it offers a valuable ground to emotionally engage

both physically and through the media with passers-by and the larger public. It also offers a ground to collectively negotiate existing rationalities and political questions that are central to the changes in living conditions taking place due to the global climate crisis. Through its transformative collectivity, bodily climate activism asserts itself as an important non-violent participation in politics, in which the socio-spatial configurations are more momentous than the individual body.

Our study centered on the human body and investigated activists' accounts of how they relate and engage with different agencies during climate activism manifestations. This study thus serves as a first step in gaining in-depth insights into the bodily meaning-making processes of climate activists. Future studies that draw inspiration from the corporeo-cartographic research tradition or the Latin-American decolonial feminist method of mapping body territories (Cuerpo-Territorio) in order to illuminate the fight against capitalist notions of exploiting nature and that include instances beyond the European context can complement this study. Regarding the theoretical framework, social constructivism has been critiqued for taking a representational approach—that is, trying to provide descriptions and presentations that mirror reality, which, according to Karen Barad among others, deems matter passive and overlooks material agency in the construction of reality (Barad, 2007). Despite this, there are bridges to be built between the two theories to conceptualize the body as a tool for demanding climate action and climate justice during activism. For future studies, the new materialist approach could be something to explore further. In line with Karen Barad's thinking, future studies might conceptualize the body not as a static entity operating in the world but instead as being "constituted along with the world or rather, as part of the world (i.e., 'being-of-the-world,' not 'being-in-the-world')" (Barad, 2007, p. 160). While Berger and Luckmann's original conceptualization of "the body as a tool" implies that the body has strict human-centric boundaries, as an author collective we acknowledge that the body as a tool is dynamic and ever-changing through its intimate entanglement in material and discursive practices that co-constitute climate activism.

Studying the body as a tool for climate activism necessitates reflexivity on the research practices that we used to conduct this research. Such reflections create a space for thought about how to position oneself as a researcher, being part of the research-configuration of people, (research) practices, ideas, and bodies as (socio-material) matter that matter. Being part of the research-configuration is directly related to the relationship one builds with interviewees as participants, the narratives being produced, and the texts that represent them, including this article. It is also a silent witness to the trust and solidarity achieved in this study process. In that sense, in future research we will build more on that trust to have participants help analyze the data and feed meaning to the themes in full negotiation about what matters in the relational practice of social change.

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The authors declare no conflict of interests.

## Data Availability

The data will remain available on a protected server of KU Leuven for 5 years upon publication of this article and will then be deleted.

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## About the Authors



**Margaret Tilk** is a researcher and artist currently pursuing a master's degree in social design at the Estonian Academy of Arts. She holds an MSc in cultural sociology from KU Leuven and a BA in semiotics from the University of Tartu. Her academic interests focus on the role of the body in climate activism and new materialism. In her artistic research practice, she intertwines sociology and performance art in post-Soviet cities, employing these mediums as means for transformative action.



**Antje Jacobs** is a joint-PhD candidate at KU Leuven and the University of Melbourne, in the departments of sociology and education. She has a background in art studies (Vrije Universiteit Brussels), as well as science and technology studies (Maastricht University). Her scholarly work bridges the arts and the sciences, exploring the complexity of knowledge creation which involves creative approaches and participant engagement. In this context, her current research explores climate change through creativity, focusing on speculative and multispecies worlding.



**Karin Hannes** (PhD) specializes in the development of innovative, creative research methods to respond to emerging social challenges, with a focus on multisensory, arts-, and place-based research designs and evidence synthesis as a meta-review technique. Her latest work involves the co-creative practice of body mapping to investigate complex experiences of citizens in relation to their social environment. She is active in the areas of urban development, citizen science, art/design and technology, social and behavioral sciences, public health, and the global sustainable development context, and chairs the European Network of Qualitative Inquiry.



# “We Know Best Because Our Skin Is in the Game”: Doing Politics Through DIY Pharmaceuticals

Natasa Stoli, Klasien Horstman , and Olga Zvonareva

Department of Health, Ethics & Society, Maastricht University, The Netherlands

**Correspondence:** Natasa Stoli ([a.stoli@maastrichtuniversity.nl](mailto:a.stoli@maastrichtuniversity.nl))

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## Abstract

In recent years, critical social science scholarship has expanded our understanding of public participation beyond talk-based and institutionally organised formats, such as citizen juries and focus groups. Building on these insights and relying on digital ethnography, we studied the practices of an online community of transgender activists producing their own hormones to broaden access to hormone replacement therapy (HRT). We argue that they pursue a political cause related to their gender identity, not by partaking in visible protest movements, but by producing what they deem as superior pharmaceuticals. In the process of DIY hormone production, the community members perform three distinct types of political work: contesting the hierarchy of expertise in biomedical science, moving the locus of pharmaceutical production from big pharmaceutical companies to the household, and producing better pharmaceuticals by focusing on affordability and responsiveness. Thus, this article delineates what public participation may look like in hostile circumstances, where it works around public spaces, maintains its invisibility, and is not directed at openly contesting formal institutions.

## Keywords

digital ethnography; DIY pharmaceuticals; public participation; science and technology studies; transgender healthcare

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## 1. Introduction

Participation in addressing matters of collective concern has been traditionally understood as something institutionalised, talk-based, and publicised (or at any rate not hidden). A common image of this type of participation involves citizens in government buildings, voting for political representatives, or partaking in



citizen juries and focus groups. Scholars at the turn of the century such as Smith and Wales (2000) saw citizen juries as a way for citizens to meaningfully engage with decision-making processes. In this example of deliberative democracy, citizen engagement takes the form of dialogue and is envisioned as a public negotiation between concerned citizens and political authorities. While this kind of participation aims at improving the inclusivity of oft-disregarded or vulnerable groups, it remains invited, discursive, and practised in explicitly designated political venues.

In recent years, science and technology studies (STS) and other critical social sciences scholarship have scrutinised the expectation that public participation needs to be centred on established governance institutions, pre-organised and often deliberative. In contrast to the analytical lens of long-established understandings of public participation (Fiorino, 1990; Habermas, 1984; Webler & Tuler, 2000), the limits of participation are reimagined to include practices that are private, mundane, and not necessarily verbal. Marres' (2012) work on "material participation" brings to the fore everyday material practices such as turning off lights and using a thermos flask as ways to engage with the issue of climate change; ways that turn the domestic sphere into a space of public participation. In a similar vein, Chilvers and Longhurst's (2016) work on public engagement with sustainable energy transitions reveals diverse forms of participation, such as engaging with display monitors in a household setting or producing counter-discourses to climate change in a decentralised environmental social movement. More recently, authors Knibbe et al. (2025) shed light on the mundane forms of care and maintenance that, for example, citizens of a low-income Dutch neighbourhood continuously perform, thereby participating in improving and maintaining the liveability of their local environment. By reconceptualising participation to include such diverse kinds of practices, this scholarship has expanded our understanding of public participation beyond the designated institutional spaces and discussion-based formats.

In this article, we build on the aforementioned insights to examine another expectation of public participation that has received less attention to date. The expectation is that public participation is about "making things public"—making them highly visible, contestable, and, therefore, of political significance (Latour & Weibel, 2005). For example, Epstein (1996) has shown how AIDS activists transformed biomedical research in the US by openly contesting medical professionals' presumed expertise in public settings. During the 1980s AIDS crisis, medical understanding of the illness was insufficient and yet, AIDS patients' voices were stifled against those of medical professionals. Epstein's influential work highlighted how AIDS activists challenged this situation by engaging with the nuts and bolts of science and relying on this specialised knowledge to protest and attack this status quo. Their intervention was highly visible, involved a protracted contestation, and ended up successfully reshaping biomedical research.

The case we discuss in this article differs from Epstein's (1996) study and much of other STS scholarship in that it is an example of public participation that does not "make things public." In addition to not focusing on discursive contestation, the community of transgender people involved in DIY pharmaceuticals we engage with in this article proceeds in a deliberately depublicised manner. They operate predominantly in online settings—anonously and quasi-hidden. They address the issue of their collective concern—the inaccessibility of hormone replacement treatments—by making their own hormones at home, prioritising action over discussion. Importantly, while community members may be producing hormones individually in the privacy of their own homes, the opportunity to do so is developed collectively, as we demonstrate further. The collective effort of a marginalised group to take control over the means of hormone

production—and, in doing so, open access to a critically important treatment—allows us to invoke the notion of public participation to characterise their activities. By producing their own hormones, they not only resist dominant meanings and arrangements but actively build viable, though hidden, alternatives.

Moving forward, this article will first delineate the primary reason why there is a need for DIY hormones at all. The following subsection outlines the challenges of aboveboard access to transgender healthcare services. The subsequent subsection discusses hostilities to the public participation of transgender people. Next, the methodology section provides information about the community itself, data generation and analysis, and ethical concerns. For the main part of the article, the results section, we will show three distinct forms of political work that the community engages in the process of producing DIY hormones for personal consumption. Finally, in the discussion, we consider the advantages of depublishing in the face of hostilities and how this community's work is still a form of public participation despite not being public in the traditional sense.

### **1.1. *Issues of Access to Healthcare Services***

The online community of transgender people we engage with in this article exists solely due to the various issues transgender people face when it comes to healthcare access. Transgender individuals wishing to align their secondary sexual characteristics with their gender identity seek medical treatment in the form of hormone replacement therapy (HRT). Several scholars have shown (Bauer et al., 2009; Kcomt et al., 2020; Roberts & Fantz, 2014; Snelgrove et al., 2012; White Hughto et al., 2015; Winter et al., 2009, 2016) that transgender individuals' access to health services is negatively affected by issues such as identity-based discrimination in and outside of healthcare settings, limited professional literature on transgender healthcare and subsequent ignorance on behalf of the medical staff and financial limitations. In this context, transgender people tend to avoid healthcare services.

Existing literature has documented various issues beyond interpersonal interactions with healthcare staff that transgender individuals face. Besides the well-documented discrimination that transgender people experience in healthcare settings, ranging from overt harassment to less blatant examples of exclusion such as gatekeeping (Bauer et al., 2009; Snelgrove et al., 2012; White Hughto et al., 2015; Winter et al., 2016), access can be inhibited by other factors. Scholars have shown that limited research done on transgender healthcare limits, in turn, the available resources doctors have to offer appropriate care to their transgender patients (Bauer et al., 2009; Roberts & Fantz, 2014; Snelgrove et al., 2012). Moreover, evidence shows that even before the point of interaction with healthcare personnel, many transgender individuals are barred from accessing the healthcare they need due to financial limitations. Roberts and Fantz (2014) and White Hughto et al. (2015) show that transgender healthcare is commonly left out of insurance plans and therefore its costs are not covered for the patients. Furthermore, transgender people face disproportionate rates of unemployment due to the societal discrimination of their gender identity and are therefore particularly burdened by high medical costs. Many scholars (Kcomt et al., 2020; Roberts & Fantz, 2014; White Hughto et al., 2015) have also noted that the expectation of harassment leads many transgender individuals to avoid or delay contacting medical services for necessary care, even for health issues besides transitioning.

Lastly, the above is relevant for the settings where transgender healthcare exists at all. In many settings, not only is such healthcare non-existent, but being transgender is also criminalised.

## 1.2. Facing a Hostile World

The purpose of this article is to explore what public participation may look like in hostile circumstances. Our case study involves a global community of transgender activists involved in DIY hormone production. Although access is not uniform worldwide, most transgender individuals face some difficulty accessing transgender healthcare. Instead of addressing this matter of collective concern by participating in explicit, aboveboard politics, this community addresses its problems by producing hormones at home. Why is public participation in addressing such matters of collective concern difficult for this community? In the literature, three important hostilities are mentioned that prevent this community from protesting and otherwise engaging with politics in the open.

Limited legal rights afforded to transgender people can inhibit public participation significantly. TGEU, a trans-led non-profit founded in Vienna in 2005, publishes a map of the legal rights of transgender people in Europe and Central Asia every year, with several indicators such as gender recognition laws, protection of transgender people from hate speech and crimes, access to transgender healthcare and more. Although transgender rights have advanced in recent years, this development is not uniform worldwide. While certain countries such as Greece have recently modified their existing legislature in favour of transgender rights ("Trans Rights Index & Map 2024 reveals," 2024b), in Afghanistan, the LGBTQ+ population faces harassment and violence, and gender reassignment has been banned since 2022 (Akbar, 2022). In the US, various states have recently implemented limitations on accessing gender-affirming care in recent years, particularly for transgender youth (Dawson & Rouw, 2024), and Russia, as of July 2022, has banned both medical and legal transition of transgender people ("TGEU deeply concerned," 2024a). In conclusion, the legal situation for transgender rights is country-specific and volatile. As such, public participation for transgender people is particularly difficult.

Societal hostilities towards transgender individuals make this kind of public participation a challenge, even in countries where laws are set to recognize and protect the transgender population. Indeed, transgender people still face considerable discrimination in society. Hill and Willoughby (2005) have defined transphobia as "an emotional disgust toward individuals who do not conform to society's gender expectations" (p. 533). A survey on transgender discrimination (Grant et al., 2011) by the National Centre for Transgender Equality (NCTE) has highlighted the deeply entrenched discrimination and abuse transgender individuals face daily in foundational institutions, such as the family nucleus, schools, the workplace, and healthcare settings (p. 8). Besides institutional and systemic discrimination, transgender people also experience ill-treatment on the interpersonal level. Lombardi et al.'s (2001) research questionnaire showed pervasive levels of harassment of transgender individuals, including verbal and physical abuse while Nadal et al.'s (2012) work showed the prevalence of particularly violent hate crimes that often go unreported. Overall, transgender people's public participation is greatly impeded by the various societal hostilities they face to this day.

Moreover, transgender activists involved in do-it-yourself (DIY) medicine production face additional hostility due to the negative connotations of DIY in biomedicine. DIYbio is a subtype of the larger DIY movement, which encompasses a variety of activities, all sharing a common characteristic: people making things for themselves, usually at home. Although most often DIY refers to home improvement projects and tinkering with furniture and electronics, its meaning has greatly expanded in recent years and has come to often emphasise distributed collective effort and collaboration. For example, the artificial pancreas system

(DIYAPS) was developed by diabetes patients who use it to continuously monitor their glucose using smart technology. It uses an open-source, community-made algorithm and is neither commercialised nor regulated (Kesavadev et al., 2020). Scholars such as Calvert (2012), Delfanti (2014), Ferretti and Pereira (2020), and Meyer (2013) have started to map the communities involved in DIYbio and their practices, with many applauding their innovation, creativity, and citizen-centric structure. The same scholars also associate it with risks and safety concerns that come part and parcel with scientific work that operates outside of any formal regulation framework. Consequently, the risks associated with DIYbio have led to hostilities, or at least suspicions, towards those who practise it.

## 2. Methodology

### 2.1. *The Community*

This article reports on an exploratory study of an online community of transgender activists involved in DIY pharmaceuticals. The community is connected through a discussion-based forum and operates primarily in English, despite having members from all around the world. All posts and comments are publicly available, and its members use pseudonyms for anonymity. The forum has a set of rules members must follow to partake in the discussions, including permitted or forbidden topics of discussion and requests for civility in communication. The forum mostly serves as a breeding ground for what the community describes as scientific work and experimentation. Their main objective is to produce hormones at home that are safe and cheap, so they can facilitate their transitioning journey using HRT. Members perform experiments related to hormone production and share their results with others. Successful experimentation leads to guides that are posted in an archive within the forum for other members to repeat at home or modify as needed. Besides this main function, the community also serves as a hub where like-minded individuals can share their concerns and receive personal advice and emotional support.

### 2.2. *Data Generation and Analysis*

Research into this community was done exclusively online in the format of ethnographic work. First author NS originally traced this community in a different social media website which led her to the community hub of several thousand members where users interacted in both public and private messages. Upon joining the forum, all public messages were available for reading. The first author informed the forum admins of her presence and plans. First author NS collected and analysed data from the forum's archive, discussion posts, and the comments therein. The data collection and analysis lasted four months. NS generated the data by initially filtering the results of the forum by time, followed by engagement level in the form of "likes." She generated data from the discussion posts with the highest percentage of engagement level since the forum's foundation, and for every month to the current date of data collection for subsequent analysis. Data saturation was reached once discussion themes began repeating themselves without sufficiently novel insights emerging. During this process, NS contacted the administrative members of the community to inform them of the research she was doing and to request interviews. Administrative members did not respond to the request for interviews but allowed her to remain a member of the forum. Since then, to respect their wish for non-engagement, NS has not contacted the community members again. Although the data generated contained a multitude of different subject matters that addressed various concerns among the community members, this specific article focuses on the data addressing how community members

traverse their gender transitioning process outside of the formal healthcare network through DIY hormone production. The analysis was particularly attentive to how these practices can be analysed through the lens of “doing politics.”

The codebook was developed iteratively and collaboratively with the authors discussing and critically questioning the emerging categories and relations between them. The codebook distinguished thematic categories, ranging from barriers to accessing transgender healthcare in hospital settings to production practices for community members who partake in DIY hormones, to the various motivations behind their participation. These categories were derived from the data and informed by existing theoretical literature on healthcare access, particularly for LGBTQ+ patients and DIYbio. NS thematically analysed the data with other team members ensuring alignment between thematic categories and units of coded text. Concurrently, NS continued reading the forum broadly to deepen emerging interpretations.

Atlas.Ti software was used to catalogue, thematically analyse, and structure the aforementioned data set. The coding scheme itself went through multiple iterations as emerging insights led to the removal, repositioning, and addition of codes throughout the data generation and data analysis process.

### **2.3. Ethical Concerns**

This article studies a community that faces diverse hostilities. Therefore, it ensures complete anonymity of the community by removing references to information such as the platform they operate in, the group names, and all personal details of the participants. NS also paraphrased all quotes from members of the community to avoid this information being used for identification purposes by ill-intentioned parties. This study was reviewed and approved by the Research Ethics Committee of the Faculty of Health, Medicine & Life Sciences, Maastricht University (FHML-REC). The approval number is FHML-REC/2023/008. We conducted our research following the relevant guidelines and regulations. In conducting and writing this study, we, as authors, have viewed our role as mediators between society, broadly conceived, and some of its endangered members. Taking much care to not endanger them further, we still see value in attempting to bring recognition to how they do politics to make these efforts count.

## **3. Results**

### **3.1. Participating By Other Means: DIY Pharmaceuticals**

We propose to view this community as performing three distinct types of political work through a depublished process of DIY hormone production: taking control over the gate to transition, expanding the circle of who can transition, and making better pharmaceuticals. This type of public participation does not display the traditional characteristics of being public, institutionalised, or discursive. Its characteristics make it both uninvited and unwelcome. Concerns around the safety of those performing biomedicine outside the regulated confines of institutional spaces coalesce with society’s hostility towards the transgender identity, leading the community to sequester itself to online spaces, where they develop ways to produce the hormones they cannot access otherwise. The community does not openly protest the formal institutions inhibiting their access to hormone replacement therapy nor do they engage in debates with medical professionals.

This reading contrasts with the community's self-representation, in which politics has no place within its borders. Indeed, community members ascribe to a particular understanding of science and politics, where politics—as they define it—is a separate thing, not to be confused with scientific work. They enforce this particular definition of science and politics in the forum's rules of conduct, which state that political discussions are not allowed. Although such a statement can be vague, various conversations among the community members showcase that, by politics, they mean discussions about political parties (either by name or by political ideology) and how each member identifies on the political spectrum. Such subject matters are viewed as a cause for conflict and are to be avoided. The community's decision to define politics in such a way effectively allows them to strategically manage the hostilities associated with participating in politics explicitly and publicly. This is how this post by a moderator in the forum describes their particular view on politics and science:

We all gain from science moving forward. Particularly Trans healthcare, whose state is honestly depressing. So yes, it's true that politics matter but science is science. If you want to be part of this community, you leave politics at the door and focus only on science. There are other places where you can have all the debates you want.

STS scholarship has often reflected on the popular conception of science and politics as strictly separate. Bruno Latour's studies on laboratory practices in the 1970s and 1980s showed the construction of impersonal objectivity in science by highlighting the mundane processes of negotiation involved in scientific claim-making. Science is not politics; in his book *The Pasteurization of France*, Latour (1988) says it is politics by other means. STS scholarship has also often delved into examples where scientists performed political work even if they did not identify it as such. De Vries (2007) discusses the work of researchers in Dutch university hospitals in the 1980s and 1990s who were investigating a maternal blood test that aimed to calculate the risk of the developing baby being affected by several chromosomal conditions. While the Dutch government decided against offering the test as a routine screening measure to all pregnant women, the country researchers embarked on a longitudinal project to improve the test by offering it to women of various ethnic groups, ages, and weights. This, in turn, normalised the use of the test among the general Dutch population, effectively introducing it as a routine screening procedure despite the government's explicit prohibition. Although the scientists did not view themselves as “doing politics,” de Vries (2017) posits that their work undermined governmental decisions, challenged the concept of routine screening and ultimately redefined what it meant to be a pregnant woman in the Netherlands. “If that isn't “politics,” then what is?”—he asked (p. 787).

This article draws on these insights to argue that, despite the community's self-presentation, their work constitutes “doing politics.” It provides them with a means to strategically respond to some of the hostilities they face and to address a collective concern by creating a hidden yet viable alternative to the restricted access to the critically important HRT. Their participation in politics, thus, takes the form of pharmaceutical production outside the rigid confines of the global pharmaceutical industry.

### 3.1.1. Taking Control Over the Gate to Transition

The first type of political work this community does is taking control of the gate to transition, by contesting the hierarchy of expertise in biomedical science. To gauge the significance of this type of work, it can be noted

that credentialed expertise grants medical professionals control over the gate to transition. In the current healthcare landscape, medical professionals are typically the ones whose expertise is deemed solely suitable to decide what treatment a transgender patient needs. As such, physicians are the gatekeepers to transgender healthcare. The well-documented obstacles to transgender healthcare that we discussed earlier imply that transgender patients are often excluded from concomitant decision-making.

As a response to these obstacles, the online community's transgender activists engage with biomedical literature on hormone production to take back control over access to health care. They read a plethora of published biomedical texts retrieved from online sources, analyse them carefully, and share their insights with the rest of the community. If possible, the information is simplified to remain accessible to all members, regardless of their biomedical knowledge level, which can vary. The goal is to acquire a deep understanding of the source material in a continuous and collaborative effort that builds a shared knowledge enterprise situated within the borders of the forum itself. The following quote, published in an introductory post within the forum, echoes this sentiment:

We should commit to supporting one another. Those against us want us to depend on professionals who don't care for us and who are unaccountable. So we should help everyone who asks us, we should help them take control of their own care. Remember: Someone who knew nothing yesterday can become an expert tomorrow!

As community members create a pocket of expertise within the borders of their forum, they aim to decrease their dependency on medical professionals. For many members of the forum, insights and information on transgender healthcare, such as HRT, found within the community act as replacements for physicians' input. Instead of scheduling a doctor's appointment, with the inherent possibility of receiving inadequate care, members choose to request aid from their fellow community members, who they view as "experts in the place of experts." The following quote by a community member highlights their quest for independence from the medical establishment:

Think of the consequences to the healthcare system of what we do: If patients can medicate themselves, what will become of doctors? What will happen to their jobs? Us DIYers are the last line of defence. If you have the raw ingredients and the knowledge, you have no need for a doctor or pharma. If you lack money or there are shortages—NONE OF IT MATTERS!

These practices are a way for these transgender activists to redistribute expertise. Although the community members do not openly contest the monopoly of expertise exercised by medical professionals worldwide, they build their own gate to transition, by creating a pocket of expertise situated outside the confines of institutionalised biomedical science and its representatives. By pushing the boundaries of who is deemed the expert in transgender healthcare, they dispute a previously well-guarded monopoly and take the first step in responsibly and safely producing their hormones for personal consumption in domestic settings.

Redistributing expertise may work towards democratising healthcare, following in line with the ideals of the maker movement, whose practices of openness and tinkering create *active makers of science* (Meyer, 2013). By redistributing expertise, transgender activists begin severing the bonds tethering them to medical professionals, effectively altering a lopsided relationship of dependency. Without depending on an external expert to allow



them entry, gatekeeping from medical professionals no longer constitutes an impassable obstacle to accessing HRT. Therefore, we can view taking control of the gate to transition as a type of political work.

### 3.1.2. Expanding the Circle of Who Can Transition

The second type of political work this community does is expanding the circle of who can transition by moving the locus of pharmaceutical production from big pharmaceutical companies to the household. Issues around accessing transgender healthcare can limit the circle of who can transition. Country-specific legal frameworks, medication shortages in the global and local pharmaceutical marketplace, local issues of infrastructure, as well as personal financial limitations can rob transgender patients of the opportunity to transition altogether. Certain countries, such as Russia or Afghanistan have legal frameworks that render transgender healthcare criminal. Even in cases where medical transition remains an option, financial limitations can inhibit access. All these lead to transgender patients experiencing uncertainty as the circle of who can transition shrinks or expands due to factors firmly placed outside their control. The challenges transgender people have to navigate in order to transition are illustrated by the following excerpt, found in the forum's archive, which also serves to frame the community members' goal of "doing it themselves":

Transitioning is a challenge. You need to have regular access to efficient medication and the price is often too high for most people who need to keep paying for expensive appointments, private insurance and all that, assuming they've met an open-minded doctor. And for some, this isn't even an option, as some of these drugs aren't available in all countries. Therefore, we DIYers decided to start doing things differently, by "seizing the means of production" in our own specific way.

This community brings their acquired expertise on HRT into effective action through DIY. Having engaged with biomedical literature on the subject, they seek out long-expired patents and other publicly available information on specific hormones. They reverse-engineer these hormone patents and create guides that any community member can follow at home. The guides are freely accessible within the forum and involve explicit step-by-step instructions, as well as the tools and ingredients needed for hormone production. Most guides focus on topical hormone treatments, where the substance is placed on the skin and then absorbed into the body. The community believes that focusing predominantly on this route of administration is safer than injecting the hormones intravenously or consuming them orally. Additionally, acquiring the needed equipment and ingredients for topical hormones requires less money than injections and is, therefore, more financially accessible. Because familiarity with biomedical literature and procedures is not uniform across the board, more knowledgeable members support the less knowledgeable ones. As many of the members "do it themselves" and share their insights, they continue the collaborative effort of building a self-sufficient and information-rich knowledge enterprise. In one of the discussions within the forum, a member provides the following statement, which illustrates the community's stance against the various mechanisms that they name "the system":

Why do-it-yourself? Well, I don't see why any of us should give our money, which we fought to earn, to some doctor, just so they can write on a piece of paper and send you to a pharmacy. Do you like being told by some fool in a white jacket what to do with your money and with your body? What about pharmacists refusing to give you the drugs you've been taking for years just because this little slip of white paper expired? Do you enjoy being part of a system that was created by big pharmaceuticals pretending they're keeping you safe but, in fact, are just profiting from you? Because we don't.

Contesting the gatekeeping of medical professionals in action allows them to understand the process of transition but does not necessarily give them the means of transitioning. Thus, further seizing the means of transition by moving the locus of production from the big pharmaceutical companies to the household facilitates their medical transition in the face of these obstacles. As accessibility expands, transgender individuals who previously had no aboveboard access are enabled to transition. They are accompanied by others who can technically access HRT via formal routes but prefer the independence DIY pharmaceuticals offer. As the community members apply their new-found expertise at home and produce the hormones they need to medically transition, they seize the means of transition. Consequently, we can view expanding the circle of who can transition as a type of political work.

### 3.1.3. Making Better Pharmaceuticals

The third type of political work this community performs is making better pharmaceuticals by focusing on affordability and responsiveness. For many community members, HRT currently available in the global marketplace is expensive without being overly responsive to their specific needs. Hormones available in the market might have insufficient concentration levels for their purposes or stage of transitioning. They might also interact negatively with certain types of medication that community members take. Due to experiencing institutional, systemic, and interpersonal discrimination that affects their job opportunities, transgender individuals tend to grapple with purchasing their medication at the market price. HRT in particular poses a challenge due to its status as a lifelong treatment plan, which accumulates costs in the long term. Hence, being unable to financially support the continuous purchase of HRT can have adverse physical and mental consequences for the transgender patient. Concurrently, HRT and other transgender healthcare treatments remain an under-researched field of biomedicine which, in turn, negatively affects the responsiveness of the end products. Essentially, the community sees the current state of HRT in the marketplace as unaffordable and insufficient for their personal needs.

In response to this, community members initially worked to lower the production cost of DIY hormones. They address the matter of cost by pursuing a concrete objective: the ideal price of DIY HRT should be \$1 per year. This goal is paramount since DIY hormones have a substantial initial cost but a long shelf-life. Raw ingredients are the most expensive part of the process but once members produce their hormones in bulk, they can use them safely long-term. While this ensures that they will have the medication they need for years, the start-up expenses can be discouraging and, therefore, community members research carefully to find global and local suppliers of the raw compounds that are as cheap as possible while remaining safe. In the same vein, they carefully weigh which tools can be replaced with cheaper alternatives and which ingredients can be safely omitted from the recipe to drive down the price. The following excerpt, from the forum's archive, showcases the extensive work put into pursuing the goal of accessible HRT:

We are researching both locally, as well as globally, for suppliers with the lowest possible cost while still verifying the purity and safety of the ingredients themselves....We have discovered that the most useful recipe right now is [commercial name], which has been reverse-engineered from a commercial product that has been in the market since [date]. We can make it even better by combining it with a recently patented [compound] that will help with absorption a lot. That way we are reducing the cost exponentially. This gets us closer to our 1 dollar per year objective! This is super important for other countries in the world, where access to HRT is almost impossible due to the financial limitations or even crippling poverty in third-world economies.

Once costs have been addressed, their next step is to personalise the DIY hormones to better fulfil the needs of individual members. Depending on their level of biomedical knowledge and their familiarity with DIY medicine production, they either start with a reverse-engineered and published guide within the forum or experiment with an entirely new recipe that has not been published yet. Some modify the ingredients, usually in quantities, to achieve a certain effect, while others keep the recipe the same but change the frequency with which they consume the end product or its combination with other treatments. They note down the effects these modifications have on their own body and share their insights with the rest of the community. For those who have access to hospital facilities, blood tests are used to monitor changes in their bodies. For those who do not have such access, physiological observations are viewed as a sufficient alternative. Successes are shared in forum discussions and once the experiments are repeated by more members with positive results, they are officially published as new guides for DIY hormone production. The following quote was found in the comment section of a personalised recipe and shows the enthusiasm with which other members respond to those who succeeded in improving their HRT:

So it needs less money to make, it makes your levels better and you get all that without having to depend on a doctor, a pharmacy, or a supply chain? Looks like we weren't kidding! Please share your experiences in forums as well, if we can teach more people how to make this themselves, we'll get more freedom and happiness in this world!

Instead of a one-size-fits-all approach, this community produces hormones that are more affordable and responsive than the pre-existing ones found in the global market, ultimately making pharmaceuticals better. Unlike the typical process of R&D that brings pharmaceutical products to the market, these transgender activists are involved in every step of the process. They ensure production costs are low enough to maximise accessibility, they research and develop hormones and most importantly, they consume them as well. They embody the role of both researcher and research subject and, as such, have the unique opportunity to modify the production process in ways that respond to very particular needs. Their experimentation works two-fold. First, it customises HRT in a way that makes it more tailored to their needs. Second, it aids in collaboratively improving DIY hormone production within the community in general. We, therefore, can view this process of making better pharmaceuticals as a type of political work.

#### 4. Discussion

One of the most common types of transgender healthcare is HRT, which transgender individuals consume to align their secondary sexual characteristics with their gender identity. Due to various issues we have explored in this article, access to HRT can present considerable challenges for most transgender individuals worldwide. We studied an online community of transgender activists who respond to these issues by “seizing the means of transition” and producing the hormones they need at home. During this process, community members democratise healthcare in three ways: by contesting established hierarchies of expertise in biomedicine, by expanding the circle of who can transition by moving the locus of pharmaceutical production from big pharmaceutical companies to the household, and by moving towards producing better pharmaceuticals by making them more affordable and more responsive than the ones available in the global pharmaceutical marketplace.

Recent STS scholarship has looked into diverse forms of public participation, including practices that are rather private, mundane, and creative. Even so, public participation is still often conceived as dependent on making matters of collective concern visible and publicly debatable. Our analysis has shed light on a community that faces significant hostilities and, therefore, avoids explicit and public participation. Instead, to continue participating under hostile circumstances, they refrain from openly challenging formal institutions and make sure to remain hidden. This case study provides a glimpse into an example of bottom-up public participation under hostile conditions, where action, rather than deliberation, takes centre stage, and talking plays a more auxiliary role. In this context, practices move forward in a deliberately depublicised manner. Additionally, our case study highlights the importance of focusing more on doing than saying when studying contemporary politics, as suggested by recent STS scholarship (Knibbe et al., 2025; Marres, 2012). While our case study can also be viewed through the lens of political resistance scholarship (Bayat, 1997; Scott, 1985), we have chosen public participation as our analytical lens because it emphasises building alternatives rather than creating obstacles meant to sabotage or exclude.

Depublicisation is key for this type of public participation. This community of transgender activists largely circumvents formal healthcare settings while still acquiring medical treatment in the form of HRT produced in domestic settings. Due to the nature of these practices, their work falls under the umbrella of DIY biomedicine. DIYbio is associated with risks and safety concerns, because of operating without top-down supervision from regulatory actors. This, alongside various hostilities related to the legal and societal status of transgender people worldwide, inhibits the community from publicly participating in politics. In response, they have created a safe and anonymous online space where members from all around the world collaborate to build a knowledge enterprise on DIY hormone production. With no interest in contesting formal institutions or engaging with the biomedical sphere in direct deliberation, the community remains self-contained. Nonetheless, their practices undermine the commercial hegemony of the global pharmaceutical industry while also reimagining the biomedical field as more citizen-driven, making it truly participatory.

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## About the Authors



**Natasa Stoli** studied philosophy and history of science and science and technology studies at the National and Kapodistrian University of Athens, Greece. She is currently a PhD candidate at Maastricht University in the Netherlands, where she employs ethnographic methods to explore knowledge practices, public participation, and informality in grassroots initiatives that contest the established structures of pharmaceutical research, development, and production.



**Klasien Horstman** has studied philosophy, historical sociology, and science and technology studies. She is a professor of philosophy of public health at Maastricht University, the Netherlands, and her research is dedicated to exploring the “public” character of public health and the engagement of public health experts and policymakers with different “publics.” She uses philosophical-empirical, participatory-ethnographic methods to study relationships between science, society, and democracy in a variety of public health practices such as (workplace) health promotion, urban health, vaccination, and AMR prevention.





**Olga Zvonareva** is focused on research situated at the intersection of science and technology studies and global health, on public engagement in health and biomedical knowledge production. Her primary research line concerns relations between scientific knowledge, technologies, and politics. She believes politics are found not only in parliaments and election practices but also in doctors' offices, R&D laboratories, and public health interventions. Due to the profound impacts of health technologies on daily life and how society functions, it is of crucial importance to study not only how exactly these impacts come about but also how citizens (can) participate in shaping them. She is especially invested in studying instances of participating in situations when members of the public are discouraged from doing so.



## Participation in Times of War: The Ambivalence of Digital Media

Olga Zvonareva 

Care and Public Health Research Institute, Maastricht University, The Netherlands

**Correspondence:** Olga Zvonareva ([o.zvonareva@maastrichtuniversity.nl](mailto:o.zvonareva@maastrichtuniversity.nl))

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### Abstract

Do digital media support or undermine democracy and freedom? Building on recent scholarship that highlights the diversity of digital media’s effects, this article begins with the premise that digital media do not clearly shape political life in contemporary societies one way or another but are instead ambivalent. The article seeks to explicate how exactly the ambivalence of digital media emerges and to arrive at a suitable conceptualisation of their role. Empirically, to capture how digital media become embroiled in very different kinds of political action, I draw on a prolonged ethnographic engagement with two war-time volunteer initiatives in Russia. Both initiatives participate in politics by assisting Ukrainian war refugees who fled in the direction of Russia, and both rely on the messaging app Telegram. However, the participation of one amounts to resisting the imperative of supporting the aggression foisted by the state on Russian citizens, while the participation of another heightens this very imperative. I engage with these two contrasting digitally mediated initiatives doing similar activities but acting on vastly different commitments to illuminate the digital media’s ambivalence. I show how digital media contribute to the creation of and cracking down on democratic openings by becoming actors in the collective action networks that strive to resist oppressive political strategies and, simultaneously, in the networks that strive to further strengthen the very same strategies.

### Keywords

authoritarianism; collective action; democracy; digital media; digital participation; participation amidst hostility; public participation; Russia; Telegram

## 1. Introduction

### 1.1. *Introducing the Puzzle*

One of the most heated contemporary debates revolves around the political role of digital media (Koc-Michalska et al., 2016; Kreiss, 2021; Persily & Tucker, 2020; Van Dijck & Poell, 2015). Do they support or undermine democracy and freedom? On the one hand, studies have shown how digital media open novel opportunities for political engagement. For example, in 2011, the Occupy movement started in the US and within a month sparked protest activities against socioeconomic inequalities in more than 80 countries through images and personal stories shared on digital media platforms like YouTube, Facebook, X (then Twitter), and Tumblr. By making it easier for citizens to connect, articulate their concerns, and act on their commitments, digital media appear to be conducive to the democratisation and broadening of public participation in politics (Bang & Halupka, 2019; Bennett & Segerberg, 2012; Theocharis, 2015).

On the other hand, there is evidence of polarising and divisive effects of digital media. These negative effects can be brought about through, for instance, the creation of insulated “echo chambers” with citizens being exposed largely to the news and perspectives that align with their own (Sunstein, 2018). They can also be brought about through digital media facilitating exposure to opposing views reduced to their caricature versions. These developments endanger mutual understanding paramount to solving collective problems in highly diverse societies. The attack on the US Capitol in 2021 is one example of how digital media-facilitated circulation of misinformation and extreme views within insular networks incited radicalisation and violence against democracy itself (Jeppesen et al., 2022).

Recent reviews that focus on the relationship between digital media and politics highlight that multiple studies conducted on the topic to date have produced conflicting and incoherent results (Lorenz-Spreen et al., 2022). It appears that digital media are inherently neither supportive nor corrosive of democracy and freedom; rather they are ambivalent. This article delves into this ambivalence and seeks to understand how it emerges. How are the contrasting effects of digital media produced? And if digital media do not clearly shape political life in contemporary societies one way or another, how can we productively theorise their political role?

### 1.2. *Introducing the Study*

Empirically, to capture how exactly digital media become embroiled in very different kinds of political action, I draw on a prolonged ethnographic engagement with war-time volunteer initiatives in Russia. Many of these initiatives emerged nearly overnight, following the escalation of Russian aggression in Ukraine in February 2022 as an attempt to resist the imperative of supporting the aggression foisted by the state on Russian citizens. Following a period of haphazard digitally mediated searching, thousands of people previously unknown to one another became connected and engaged in exploring what could be done. The mode of action that these newly connected volunteers have mostly settled into focuses on assisting people from Ukraine while in Russia.

People from Ukrainian territories that are occupied or have become zones of active warfare often can only flee in the direction of Russia. Consequently, the backbone of the new ecology of dispersed grassroots volunteer collectives is a host of collectives that ferry Ukrainian people across Russia toward the European Union (EU).

This backbone is surrounded by smaller initiatives that have coalesced around arranging medical assistance and various other types of support for these EU-bound people, as well as for those who, for the time being, remain in Russia. Importantly, the overall ability of the newly emerged volunteer initiatives to assist hinges on the messaging app Telegram, as I show below.

What allows this study of new war-time volunteer initiatives to engage with the ambivalence of digital media is that while the ecology of these initiatives is largely contentious, there also exist other collectives. Such collectives are similarly dedicated to assisting people from Ukraine, but their assistance activities do not mount resistance to the war-waging authoritarian state. Instead, through their activities, these initiatives—commonly referred to as “patriotic”—aspire to extend the reach of that very same state. In this article, I zoom into two initiatives—one contentious and one patriotic—to accomplish two things. First, I trace the morphing of scattered individuals into efficient and stably functioning grassroots collectives, highlighting how Telegram has centrally featured in the process, and argue that volunteering becomes a means of participation in war-time Russia. Second, I engage with two contrasting digitally mediated participatory initiatives doing similar activities but acting on vastly different commitments to illuminate the ambivalence of digital media. I show how digital media contribute to the creation of and cracking down on democratic openings by *becoming actors in the collective action networks* that strive to resist oppressive political strategies and, simultaneously, in the networks that strive to further strengthen those very same strategies. I would like to stress here that this article is not about (digital) volunteering as such. Rather it is about how in the specific situation this article focuses on, volunteering becomes a means of political participation and how digital media are involved in making this participation happen and producing highly divergent results.

## 2. Participation by Other Means

Before outlining the methodology of this study, I pause here to consider the notion of participation because in what follows I propose understanding the work of the volunteer initiatives described in this article as a form of participation in politics.

Traditionally, participation has been conceived as focused on electing or otherwise influencing state officials (De Moor, 2017; Theocharis & Van Deth, 2018). This thinking is noticeable in classic definitions of participation, such as the one offered in 1972 by Sidney Verba and Norman Nie, who considered participation to be “those activities by private citizens that are more or less directly aimed at influencing the selection of governmental personnel and/or the actions they take” (Verba & Nie, 1972). Political theorists have never denied that citizens influence societal life in many ways, including those not directed at the state. However, they have tended to draw a line between activities that target the state and thus are deemed to be “political” participation and those that do not and are correspondingly termed “civic” or “non-political” participation (Ekman & Amnå, 2012).

More recently, scholarly concerns about accurately diagnosing the state of participation in contemporary societies—Are people withdrawing from politics? Are they increasingly engaging in politics but on their own terms?—have inspired efforts to redefine participation. One popular line of reasoning has been to suggest that recent technoscientific advances and novel risks and concerns associated with these advances have stimulated the expansion of participation beyond state political institutions and formal avenues for exerting influence on them. In the words of the authors of a recent review article, “a rich stream of research has since

applied the political participation concept to unconventional political acts, such as protesting, and even various forms of civic engagement that are not obviously political in nature” (Ruess et al., 2023, p. 1497).

There is also another way of looking at participation. It involves decentering the state, its officials and their decisions more radically, and instead focusing on issues (Chilvers & Kearnes, 2016; Marres, 2007). An issue could be, for example, the installation of 5G masts in a community as Noortje Marres described (Marres, 2023). The issue of 5G masts entangles mobile phone users, residents, nature lovers and business owners whose concerns are in conflict. It throws into stark relief shared dependencies on the same atmosphere, land and infrastructure; diverse threats to livelihoods posed by mutually challenging ways of living; and associated societal divisions. If we look at participation in an issue-centred way instead of state-centred, we can see the continuous and shifting co-existence of different interrelated participatory activities that adopt varying formats and varying degrees of contentiousness, explicitness, and orientation towards the state (Baim-Lance et al., 2019; Jansky & Langstrup, 2022; Marres, 2015; Stewart, 2021; Tironi, 2015). For example, Chilvers et al. (2021) showed that in the UK, the issue of energy transitions has generated engagements as diverse as protests, participatory dance and performance, energy cooperatives, everyday energy-conscious practices such as heating and commuting, media engagement, and government-sponsored consultations and behaviour-change initiatives. By starting to explore participation from issues, it is possible to notice forms of participation that are rare or even unique to the issue in question and to avoid being locked on to more familiar forms, also leaving aside the often-criticised distinction between political and civic participation. Therefore, I approach the volunteer activities described in this article from an issue-centred perspective, viewing them as one of the ways in which citizens strive to affect the issue of their concern—the war—despite mostly being explicitly disinvited from doing so.

### 3. Methodology

In this article, I report some of the results of a prolonged ethnographic engagement with novel war-time volunteer initiatives in Russia. Here, the operation of two such initiatives is analysed; however, I have followed the work of many more (Zvonareva, 2024). Both initiatives examined here rely on Telegram, which is one of the most popular messaging apps in former Soviet locations with 900 million monthly active users as of March 2024 (Murphy, 2024). It was created by Russian entrepreneurs Pavel and Nikolai Durov in 2013 and has a reputation of a tool capable of protecting communication amidst political persecution. This reputation has been supported by Pavel’s confrontations with Russian authorities, his subsequent exile, and Telegram’s stated adherence to privacy, security, and freedom of expression (Wijermars & Lokot, 2022).

My analysis in this article draws on several types of data. First, I have followed open chats of both initiatives. I started following the chats of the contentious initiative, which I have named here *On the Move*, in May 2022, read back to the first available messages from April 2022, and have continued to follow them until now. I started following the chat of the patriotic initiative, which I have named here *The Circle*, in December 2023, read back to the first available messages from March 2022, and have continued to follow it until now. *On the Move* and *The Circle* are not the real names of the initiatives. Reading chats from both initiatives, I took notes, wrote analytical memos and selectively saved posts without posters’ usernames and other identifying details. Second, I conducted 52 online semi-structured interviews (Green & Thorogood, 2018, pp. 115–146) with contentious volunteers, some of whom were active only in *On the Move*, others contributed to the functioning of several initiatives, including *On the Move*, and others did not work with *On the Move* directly,

but were aware of it and sometimes collaborated with this initiative or recommended it to those who could benefit from its assistance. I did not talk to anyone from The Circle, assuming animosity from their side. This asymmetry was compensated by a search of media which generated the third type of data I rely on in my analysis here. I collected all media appearances of The Circle found using the name of the initiative and/or its leaders and/or versions of the word “volunteer” in Yandex.ru. On the Move, as described below, operates in a depublicised manner, therefore there is very little data of this kind about this initiative. The Circle, on the other hand, strives to attract attention, with its leaders giving multiple interviews to regional media and bloggers, and its work featuring in numerous news reports.

Analysis of these data has proceeded simultaneously with their generation and as a part of a larger inquiry into the ecology of the new war-time volunteer initiatives in Russia. I analysed interview and media data thematically (Green & Thorogood, 2018, pp. 249–284), looking for salient themes coming from the data and considering them in light of the theoretical literature on public participation and the societal effects of digital media. I used these data in combination with the insights gained by reading the chats to create a timeline of developments for each initiative and to sketch their operation processes internally and externally, in connection to other initiatives and collectives. Finally, I relied on the analysis of the chat data to understand the nuts and bolts of the initiatives’ daily work. My thinking throughout the analysis process has been checked and aided by regular discussions with my research team members; at a more advanced stage, preliminary results and the process of arriving at these were presented to colleagues at the Department of Health, Ethics and Society and participants of the workshop “Participation and STS Sensibilities.” I critically reexamined themes, patterns and conclusions identified as shaky and reinforced or corrected these. I also continuously reflected on my own positionality in this research and noted my reactions, emotions, and concerns alongside the research process and how these related to my fieldwork decisions and analysis. In contemporary qualitative social sciences, there is little expectation of researchers engaging with their fields of study from a position of absolute neutrality and detachment (Nikulkin & Zvonareva, 2024). However, there is an expectation of being transparent and accountable and I took care in being both in my analysis and my thinking throughout as documented in this article.

This research presented ethical challenges, chiefly related to not compromising the safety of endangered volunteers—in this article, On the Move volunteers. The situation of The Circle volunteers is different because they are currently far from being endangered and this research is unlikely to make them any more vulnerable in the future, given their extensive publicity and outspokenness. To protect On the Move volunteers, I kept collection of identifying information to a minimum, anonymised the data—including deleting original interview recordings after transcribing them myself—and stored the data securely. I also anonymised all information concerning The Circle volunteers in my publications, including this article, for symmetry. I involved the endangered research participants in the process of minimising risks. I wrote down the results of my analysis in Russian in the fall of 2023 and shared them with those who had spoken with me. This text also circulated within the wider volunteer community, being forwarded from volunteer to volunteer. Sharing the results first with the volunteers served two purposes: First, I was able to check my interpretations and receive critiques and additional insights. Second, volunteers themselves checked already anonymised results for potential safety issues. This research was reviewed and approved by the FHML Research Ethics Committee at Maastricht University (the approval number FHML-REC/2022/110).

## 4. Results

In this section, I introduce two volunteer initiatives, On the Move and The Circle. Both assist war refugees from Ukraine in Russia and centrally rely on Telegram for their work. They are also vastly different. Conversations with the On the Move volunteers revealed a sense of desperation caused by association with the war-waging country. Typically, stories of how one became a volunteer would sound like this story shared with me: “When the war started, it was devastating, you cannot do anything, you can just sit around and watch. And some three weeks later, I heard that somebody, somewhere is somehow helping, that refugees are coming”. My interviewees would then proceed to join the volunteer collective in an effort to act on their disagreement with the war. The Circle, in contrast, champions the war. Below, I delineate the mechanisms and processes of the two initiatives’ operations and highlight the divergent roles Telegram plays therein.

### 4.1. Contentious Volunteer Collective: On the Move

On the Move, the first volunteer collective I focus on in this article, is hard to define as it has no specific location, leader or official representatives. The most concrete manifestations of this initiative are several group chats on Telegram. These group chats are open, which means that anyone can join without the approval of the chat admins. But first, one needs to find these chats, which is not straightforward considering that links to them are not shared publicly on social media. Online searches do not typically lead directly to them, and very few journalistic publications cover On the Move’s work. Instead, links to the chats are passed from person to person: From those who have already relied on the initiative’s assistance to those who may benefit from it and from those who contribute to the initiative’s work to those who are searching for ways to act on their opposition to the war.

Upon opening any of the On the Move chats, one would notice that it is mostly filled with messages marked as “tasks,” such as the message below:

Volunteer 1 [July 2024]

#task

Please help me cover the costs involved in two requests:

1. Costs of meals and accommodation for a family with three children in transit 5000 + 2900 already covered 🙏🙏🙏
2. Costs of vaccinations and travel documents for two cats 5800 + 2000

If one lingers for a bit, one would then notice that within several hours after posting, the hashtag #task on top of such messages usually changes to the hashtag #completed. A note was also added to the message above: “Both requests are addressed, families and their animals are safe.”

What would be impossible to observe directly though, is the distributed system of flexibly organised interactions of which the open chats and tasks posted in these chats are only a small part. Requests for

assistance are continuously collected, cases are distributed between volunteers, various resources from tickets and contacts of volunteers abroad to wheelchairs and medical care are secured, and progress is tracked. In the absence of formal hierarchies, chains of command and external funding, On the Move functions like clockwork. To understand how such a collective action of thousands of people has become possible, let us first trace the emergence of this volunteer initiative.

On the Move started with a small group of acquaintances living in Russia; mostly women, mostly with kids. At the end of March 2022, upon realising that people fleeing from Ukraine would sometimes find themselves in Russia, they began thinking about how they could assist. One of them, Natalia, created a Telegram chat to ease the discussion and called it Unite. It was not clear how to contact people from Ukraine, where they were, what was needed, and how to self-organise. Chat participants began by gathering information and organising it into sharable instructions, such as guidelines for leaving Russia for the EU.

As the Unite chat was open, a link for joining it, as well as links to newly created instructions, began being forwarded from person to person beyond the initial participants. In a matter of days, the chat grew beyond the initial small group of acquaintances to several hundred members who were mostly strangers to each other. Inevitably, a question arose about how to connect those who would like to assist with those who would like to receive assistance without openly sharing information about either. To address this, about a week after the birth of the initial Unite chat, three new Telegram chats were created. These new chats would later become the heart of On the Move. While the initial chat aimed to connect those eager to provide help with each other, the new chats aimed to connect people from Ukraine in Russia with those who wanted to help. The new chats were arranged according to three different scenarios: The first chat was for those who were in transit towards the EU via city A; the second chat was for those in transit towards the EU via city B; and the third chat was for those staying put for the time being. These chats were open and the link for joining was forwarded personally to all relevant contacts the chat participants could think of in an effort to reach those they intended to support.

Suddenly, the chats On the Move A and On the Move B started growing quickly, mostly due to the people in cities A and B joining. On the day these chats were created, messages such as the ones below poured in continuously:

Person 1: I can provide food and necessary stuff, pay for taxi, can bring food to the train or bus. Probably can do something else, I just do not know yet what exactly [18:40]

Person 2: Hi! I live in the city B. I can help with anything [19:03]

Person 3: Hello, I live in the city B, can help with food, clothes, pack necessary things to go, transport to a train, pass something, pay for a taxi [19:09]

Person 3: + there is a spare room (can accommodate 2 people). There is a dog at home [19:15]

Person 4: We can accommodate 2 people (queen size bed) in a spare room, city centre, not far away from the railway and bus stations. Will provide everything necessary. We do not have a car, but can order a taxi [19:24]



Concurrently, ways to add more structure to the assistance provision began to be explored as it became abundantly clear that, otherwise, “[i]n a couple of days the chat will turn into an endless stream of messages where it is impossible to find anything,” as one volunteer put it in On the Move B in April 2022. As a result, about two weeks after its inception, the initiative—now collectively known as On the Move (though it also assists those who are not on the move)—had developed into a system comprising a number of components: a Telegram bot for receiving requests; bot operators for communicating with request authors; online tables for recording requests and progress in addressing them, accessible only to a limited number of volunteers, including bot operators and individuals known as coordinators; and thousands of other volunteers who take on discrete tasks assigned by coordinators in the open chats.

The bot operator and coordinator roles have become defining for the On the Move initiative. The involvement of bot operators has been necessary because the diversity of the situations and the needs of those requesting assistance prevented the standardisation and, hence, automation of request collection. Instead, when a request for assistance was sent in via bot, an operator would ask the author a variety of questions to figure out a suitable way to assist in any specific case and would forward the request with its details accordingly. Coordinators are volunteers who take on specific requests and take care of addressing them fully, securing necessary resources, making all the arrangements, and maintaining continuous contact with those whose requests they took up. Volunteers who were ready to be coordinators were asked to fill in a dedicated form and were allowed to coordinate and have access to all internal data and processes only if they were known personally by somebody from the initial group or after a lengthy check and interview. Subsequently, coordinators came to specialise in either assisting those leaving Russia and/or assisting those who stay for the time being.

In a matter of days, a donations-fed ticket fund was attached, and new specialised chats emerged to support the initiative’s operation, such as chats of car owners who took on transportation tasks forwarded to them by coordinators. An internal knowledge database began to be assembled, containing information helpful for assisting in different situations and detailed instructions for volunteers. Safety rules were also developed, including a strict rule enforced by moderators to avoid discussing anything unrelated to assistance provision in the three open chats.

This speedy growth and extensive self-organisation came as a surprise to Natalia and her friends who joined her in the initial Unite chat. They did not foresee their little group becoming the seed that, planted in the digital environment of open Telegram chats and Google Forms, would produce a network with thousands of volunteers working together. Two and a half weeks after she created the Unite chat, Natalia closed it because it had fulfilled its purpose. After the Unite chat was closed, Natalia remained involved in the operation of the On the Move initiative for several months, subsequently withdrawing from it. As the assembled volunteer collective settled into its distributed and nonhierarchical way of operating, it proceeded with its work.

#### 4.1.1. Digital Media and Depublicised Contentious Participation

As can be gleaned from the previous section, digital media, specifically Telegram, featured significantly in the emergence of On the Move. Let us now examine the initiative’s current steady functioning and, specifically, the involvement of Telegram therein. To this end, below I describe an episode that highlights several digitally mediated characteristics important for understanding how On the Move operates.

One day, this message was posted in On the Move B chat:

#Task from coordinator. A family from [city in the occupied Ukrainian territory] is now in [a village in a Russian region close to Ukrainian border]. Husband, wife, child, and an immobile grandmother of 90 years old. They need food and also the grandmother needs adult diapers, size XL. If anyone is willing to assist, send me a PM [10:04, October 2022]

I read this message and sent a personal message to the author, let us call her Amina, about 1.5 hours after she posted:

Me: Hi! Is assistance for the family in [the village] still needed? [11:44]

Amina: Hello, yes [11:45]

Me: How should it be organised? Is there delivery or is it better to just transfer money? [11:46]

Amina: We don't transfer money. There is Ozon [large online store with delivery service], unfortunately this is the only thing present there. [11:49]

Amina: Look, there are several people who volunteered to contribute financially. But I need somebody who would make the order. I do not have time. Can you [11:49]

Me: yes, I can do it in the evening. Will sit down at 9 and order everything [11:50]

Amina: ok. Then I send everyone willing to contribute financially to you? [11:51]

Me: ok. I also need a pickup point address and food preferences. Will report back in the evening [11:52]

Meanwhile, Amina shared my Telegram username with others who wanted to chip in. I received messages from four people one after another, all saying that they wanted to contribute and asking how it should be done. I gave each of them my phone number, which could be used as an identifier for transferring money to my bank account. In the evening, I opened the Ozon website. After the order was placed, I messaged everyone who contributed with a screenshot of the order. I sent this screenshot to Amina as well, followed by barcodes the recipients would need to collect the packages from their pickup point. Amina passed the barcodes to the family, who collected the packages within the next few days.

In this episode, we can notice several digitally mediated characteristics of the operation of On the Move. The first is *connectivity*. I get in touch with Amina; four other people get in touch with me; we cooperate and end up remotely arranging the delivery of several packages to a family. We have never met or heard of one another. We are not near each other. Yet, we are connected and are doing something together.

Our connection and cooperation take place in a matter of minutes, which points to the second characteristic of the operation of On the Move—*instantaneity*. I exchange just a couple of phrases with Amina and others and financial contributions arrive in my account. I am placing an order without leaving my table.

Immediately, everyone involved is notified that the task is completed, and pickup information is forwarded to the recipients.

While our cooperation looks entirely spontaneous, it is also organised: Recipients of the packages I end up ordering requested assistance via the bot operator who recorded their situation in a standardised table; Amina is designated to manage the assistance provision; there is an established Telegram chat with a large membership where Amina can easily find resources; and she is going to follow up on the family and work to assist with other needs as well. The organisation is not too fixed though. Formally, it does not exist as there is no legal entity, registered name or leader. There are no hierarchical chains of command, not even clear boundary separating the collective from others: I am just a person about to donate some money but suddenly, I am coordinating other donations and their usage. Such organisation can be called fluid. It is also largely hidden because all that is visible to most people is the open chat and the task posted there, while everything else, including how requests arrive, are taken and followed up on, is not. The phone numbers and faces of the volunteers are also invisible: Most use the option of hiding their numbers and do not use their photos as profile pictures. So, in addition to connectivity and instantaneity, *fluid and largely invisible organisation* is the third characteristic of the volunteer initiative's operation. All three characteristics are digitally mediated, with Telegram being central for the mode of operation (and participation) thus shaped.

It is important to note that On the Move as a whole strives to remain hidden as well. A widespread practice of charging those critical of the Russian invasion of Ukraine with “discrediting Russian armed forces” and “spreading misinformation” enabled by the new laws in force since March 2022 places the collective in a precarious position. For instance, On the Move acquires resources internally without overt public appeals. Thousands of volunteers connected through the On the Move open chats participate, with different intensity, in the initiative's operations. These volunteers routinely take on various tasks that coordinators post in the open chats, such as meeting and hosting people, finding and transporting wheelchairs and suitcases, and ordering packages with necessities. Volunteer members of the On the Move chats also respond to fundraisers the initiative announces from time to time to collect additional funds for such purposes as supporting the transportation of people with complex health conditions. These fundraisers are only announced internally, in the chats, and are normally closed within a day. Thus, since its emergence, On the Move has assisted thousands of people, while barely leaving public traces anywhere beyond the chats themselves. These measures do not make the initiative completely invisible; with some effort, open chats can still be found by anyone. At the same time, On the Move leans heavily towards remaining hidden in a sense of limiting outward signs of its constant activity.

Drawing on the issue-centred view of participation (Marres, 2007), in the above we can see that the war has become an issue of collective concern and that by taking it upon themselves to act on this issue, volunteers of On the Move and other related initiatives have emerged as a contentious public. This public participates in politics under hostile circumstances not so much by talking, but by digitally mediated and de-publicised doing. The participation proceeds persistently through countless decentered and mundane acts like arranging transportation and necessities that together contribute to the possibility of a more peaceful future.

#### **4.2. Patriotic Volunteer Collective: The Circle**

The Circle, the second collective I focus on in this article, at first appears to be very similar to On the Move: It is a volunteer initiative that focuses on assisting people from Ukraine in Russia and its existence is most

immediately noticeable on Telegram, where it exists in the form of a single open chat. However, it is very different. Let me begin this section with an illustration of this difference.

I came across The Circle while mapping the landscape of the newly emerged war-time volunteer initiatives in Russia. While On the Move works across internationally recognised Russian territory, many other initiatives work in smaller locales. At the moment, I was focusing on a region close to the border with Ukraine; let us call it the Border region. Upon assembling a short list of links to volunteer initiatives I had seen being shared with those searching for assistance in the Border region, I opened the first link on my list. It led me to The Circle's group chat on Telegram. The chat description simply said:

The main Border chat for refugee assistance. Here help can be requested or offered. We also invite volunteers and concerned citizens.

I proceeded to read pinned posts. The first stated that the assistance provided consisted of distributing packages with food and other necessities. To receive a package, individuals and families needed to fill in a Google Form, thus entering an electronic waiting list. Other pinned posts showed that The Circle also collected and systematised a lot of information in the form of instructions with titles like "Staying in Russia" (including information about registering one's place of residency and translating documents), "Applying for Russian citizenship," "Daily life" (including information about health care and currency exchange), and "Car" (including information on how to obtain a Russian driving license). Scanning the instructions, I noted that the information offered was mostly relevant to staying in Russia.

Then I proceeded to read the chat itself, starting from the earliest posts in the spring of 2022, in which people requested and offered free items like drying racks, blankets, children's clothes, and strollers. Other posts were from families searching for places to live in the Border region, often inquiring about houses in the countryside to accommodate pets they had taken with them. Some people posted information about job vacancies, mostly for cleaners, cashiers, car mechanics, and gardeners. The Circle admins posted pictures of boxes filled with preserves, cereals, vegetable oil, and all kinds of food with long shelf life. A short exchange at the end of October 2022 caught my eye:

Nina: Peace to everyone

I want to express my gratitude to Ivan for responding and helping!

Ivan, you helped us a lot and my father also thanks you! [21:02]

Ivan: May god grant you peaceful sky!!! We are one people. Will survive the difficult times and all will become well. And then we will join at one table. There will be Ukrainian dumplings. And Ossetian pies. And Belorussian potato pancakes. And Russian mushrooms. There will be everything. The country is big. But the people are one!!! [21:08]

Ivan in the exchange above was The Circle's creator, often referred to as such or as "the head" of the initiative in the chat. The post mentions peace but Ivan also goes on to elaborate that, apparently, the condition for peace is a unity of Ukrainian people, as well as of Belarusians, Ossetians, and various unnamed others, with Russian people in one single country. This is when it dawned on me that The Circle was different.

Up until that moment, I was tracing the work of volunteers who assisted Ukrainian people in Russia, feeling devastated by their country's attack on its neighbour and attempting to resist the state-imposed imperative to support the war. Those volunteers did tell me about "others"—often called patriotic volunteers—who also provided assistance but pursued entirely different aims. The two did not collaborate, I was told. Further in The Circle's chat, I saw an indication as to why, in Ivan's response to someone asking about how to find volunteers who transport people from Ukraine to the EU countries:

We do not transport, and we do not welcome this decision. The EU wages a war against everything slaviv. Meaning against you and us!! We are one people. And must overcome and stop this together. Place the west in its place and build our peaceful life!!

I offer you to stay in PVR [state-run temporary residence centre]. It will be much easier for you.

The Circle was different from On the Move in that this initiative assisted people from Ukraine in Russia as their fellow countrymen who suffered in the process of "being freed." For The Circle, assistance was certainly not resistance. Instead, it was more of a contribution to a cause of reuniting the people who were, somehow, meant to be one.

#### 4.2.1. Digital Media and Highly Visible State-Aiding Participation

Ivan created The Circle Telegram chat in the spring of 2022 and originally invited several people he knew to join. He has lived in the Border region since the 1990s, worked as a small business owner and wrote a fiction book, which led to him becoming a member of the Union of Writers of Russia. The detail about the Union of Writers membership is important because, before the intensification of Russian aggression against Ukraine in February 2022 and before the emergence of The Circle, Ivan had participated in multiple visits arranged by the Union to the Ukrainian territories occupied by Russia in the Donetsk region. He did so because, by that time, he had come to firmly subscribe to the idea of the so-called all-Russian nation, which proclaims that Russians and Ukrainians are one people. Later on, this idea became central to the operation of The Circle.

In the period between the spring and fall of 2022, The Circle's chat grew considerably, not least due to actively "going public" in regional media. In contrast to the anonymous and reserved On the Move, The Circle had a public face—primarily Ivan, associated with it and sought to be in the spotlight, promoting its work and ideals. In September 2022, following a highly public confrontation that concerned credit attribution and personalities of different volunteers, The Circle saw a group of volunteers leaving and subsequently starting a state-supporting NGO with a mission of supporting refugees arriving in the Border region. Upon this departure, the ideological formula of Russians and Ukrainians being "one people" became a refrain incessantly repeated in The Circle's Telegram chat communication, in messages like this one from November 2022:

Ivan: In a large family there are three men. They have one single warm jacket. We are giving one more, but jackets are needed for all. We are one people. Peaceful sky to everyone!

Importantly, in the context of volunteer assistance provision, this regular invocation of "one people" achieves more than a simple repetition. Attached to specific activities—sharing a jacket, delivering food

packages, providing diapers, blankets, and other necessities—the “one people” formula ceases to be mere abstract rhetoric and instead becomes more *alive and tangible*.

Posts with information about assistance provided, written in the form of an acknowledgement by those who received it or in the form of a report by the volunteers, are simply followed by a brief interpretation of the assistance as an expression of “we are one people.” Regular rehearsal accords this pairing stability and a sense of self-evidence: Assistance is a visible and tangible indication of the trueness of the “one people” formula, whereas “one people” is the ultimate “higher” meaning of various acts of assistance. Following Ivan, other participants of The Circle’s chat have also started using “one people” in a similar way, animating it by attaching it to concrete acts of assistance.

For a time, The Circle’s chat only occasionally mentioned the existence of those who are against the “one people”—the enemy. However, since the summer of 2023, the initiative’s chat has exhibited explicit indications that The Circle has embraced a new type of assistance provision, which has allowed a more direct engagement with the idea of the existence of the enemy. This is a provision of assistance to the Russian military. From that moment on, photos of humanitarian aid started being interspersed with photos of car trunks packed with supplies for military personnel, as well as photos of satisfied recipients accompanied by text such as: “Delivery from [a city in Russia]. Sorting and sending to the front line for our fighters. Everything for a good cause. Everything to help the guys. Everything for the victory!!!” (June 2023). In July 2023, the following message was posted in the chat to inform the chat participants of The Circle’s shift in focus:

Friends (especially those who joined us recently), apart from providing food packages, household cleaning products and other stuff to refugees, self-organisation [The Circle] works on the following:

- ☑ help with making camouflage netting for the front lines,
- ☑ production of trench candles,
- ☑ knitting socks for soldiers,
- ☑ collecting donations for purchasing and producing “dry showers” – for hygiene purposes in the field environment,
- ☑ collecting donations, purchasing and transporting aid for the territories freed from nazis.

These are food, household cleaning products, children’s books, textbooks, movies, bed linen, crockery and appliances. Everything that is desperately needed by people who went through the horrors of war in basements 🙏

We very much need all help from all not indifferent people!

Join in and we together will help our soldiers bring victory and peace to our Motherland sooner!

By 2024, The Circle’s deliveries to the Russian military units in or close to the Border region have become regular and include a much broader assortment of items than mentioned in the post above, such as tents,

accumulators, thermowear, sleeping bags, and cooking appliances. The deliveries are regularly reported in the chat with descriptions of the difference they make and highlights of the importance of supporting “our guys.”

By providing assistance to the military and showcasing it through its Telegram chat, *The Circle* helps to reinforce the notion of “the enemy” presented in the official rhetoric, making the fight against this enemy more tangible and urgent. As a result, “the enemy” remains vague, referred to variously as “the west,” “nazis,” or more broadly as those who oppose “the Russian world.” However, “the enemy” does gain a sense of materiality by being linked in the chat to concrete examples of “our” soldiers, who wear socks provided by volunteers, sleep in bags provided by volunteers, and eat food cooked in pots provided by volunteers. Through this connection, those who these concrete soldiers resist become more real, animating and grounding the abstract “enemy” proclaimed by the official ideological discourse. Moreover, by pairing assistance provision to refugees with assistance provision to military personnel, the operation of *The Circle* initiative adds coherence to a heap of officially produced ideological formulas. It conjures up “one people” united together against “the enemy,” with this entire construction concretised and grounded in specific observable activities, or, in other terms, *animated* and, thus, powerfully reinforced.

Thus, we can observe how specific digitally mediated characteristics emerge in the operation of *The Circle*. These characteristics differ from those identified in the operation of *On the Move*, despite both collectives using the same digital medium, Telegram. I do not mean to suggest that there is no *connectivity*, *instantaneity*, and a *flexible, partly hidden organisation*—the characteristics that I highlighted in the case of *On the Move*—in how *The Circle* operates. These are present in the case of *The Circle* too, but their comparative importance is much less than the importance of what can be termed, following my analysis above, *animation and tangibility*.

The issue-centred approach to participation (Marres, 2023) allows us to view volunteer collectives, exemplified in this article by the *On the Move* and *The Circle* initiatives, as a deeply divided public. They are similarly concerned about the war and even act on their concerns in a somewhat similar manner—by providing assistance. Yet, their conflicting commitments create a split between them and their respective digitally mediated participatory practices are only widening this split. That the activities of the incompatible groupings within this newly emerged public are driven by concerns over the same issue does not compel them to engage with each other, explicate points of conflict, or stage a contestation. Unable to completely escape each other, they remain tied together, not least by their Russianness, yet proceed to participate in building mutually exclusive futures.

## 5. Discussion and Conclusion

Throughout the sections above, it is possible to notice that while both *On the Move* and *The Circle* are volunteer initiatives dedicated largely to assisting people from Ukraine while in Russia, what they end up doing is actually quite different. For *On the Move*, this volunteer assistance provision becomes a way to practice contentious public participation. This initiative operates in a non-democratic situation, where law enforcement and security agencies have a wide array of oppressive laws and other means at their disposal to effectively crack down on attempts at explicitly contentious engagement with politics. Correspondingly, public participation, in this case through volunteer activities, is largely depublished: Volunteers do not attempt to engage directly with state officials, stage public debates, or influence media agendas with the intention of attracting attention to their cause. Instead, they assemble a large, previously non-existent,



flexible network capable of efficient collective action. In essence, this network is quietly and relentlessly creating the possibility of an alternative to a world where they are citizens of the war-waging country.

The Circle's activities can also be defined as public participation practised via means of assistance provision. Like contentious *On the Move*, this initiative attempts to deal with the issue of collective concern—the war—in ways that are unscripted and configured spontaneously, as this patriotic initiative is not organised by the state and its activities are not ordered by the officials. But in contrast to *On the Move*, which pursues resistance, The Circle is certainly not contentious towards the state or state-initiated actions. Instead, it creatively adds to, develops, and co-shapes the dominant meanings, political strategies and the state itself. And public participation The Circle enables through its volunteer activities is highly visible. What The Circle engages in, then, can be called the co-construction of the imperative for the Russian citizens to support the war.

Both patriotic and contentious volunteer initiatives discussed in this article rely heavily on digital technologies to connect members within their disparate groups and to take action. That both use Telegram in their operation makes the ambivalence of the digital media particularly vivid. Digital media are ambivalent in terms of their liberating and oppressive potential: The previous section documented how some digitally mediated volunteer practices mount resistance to the authoritarian state, while others deepen the authoritarian state's reach and oppressive capacities. They are also ambivalent in the sense of their connective and divisive effects: The previous section highlighted how Telegram helped piecing scattered and disheartened individuals together into the networked antiwar collective *On the Move* capable of taking a large-scale action that contributes to the possibility of a more peaceful future. This same digital medium laid bare and perhaps heightened irreconcilable divisions between the commitments of this collective and what appears to be its polar opposite twin, The Circle.

This picture where digital media could have any number of effects and be involved in collective efforts to address any number of concerns may give an impression of digital media's instrumentality. Digital media may look like tools that are simply being employed by users to pursue their diverse ends, something that has been termed "dual-use" in scholarship (Lorenz-Spreen et al., 2022). I want to stress, though, that this is not the most productive way of thinking about digital media. While digital media do not determine how they are used, the opposite is also true: Collective goals do not solely dictate what is achievable through digital media involvement. To make sense of the ambiguity sketched above, we would do well to remember that digital media themselves do matter but how exactly they matter is always configured (and reconfigured) in interactions between specific digital media and their users in specific situations.

From the previous section, we could see that *On the Move*'s operation is aided by Telegram-mediated connectivity, instantaneity and flexible, partly hidden organisation, while The Circle relies on animation and tangibility, to an equal extent mediated by the same Telegram app. So Telegram, its architecture, functionalities, and constraints do matter in terms of what both participatory collectives are capable of doing. Importantly, neither of the characteristics above belongs to Telegram itself. Instead, they are co-produced by Telegram and its situated uses in wartime volunteer work in Russia. Among others, Elisabetta Costa offered to think about such digital media affordances in relational terms to highlight the process of their locally specific configuration in practice (Costa, 2018). However, most discussions on the political role of digital media to date have leaned towards viewing digital media and their effects in more

deterministic tones with media either expected to have relatively stable properties that produce similar effects or viewed as fully amenable to human intention.

Taking the above reflection into account, within the study reported here we can think of Telegram as an actor in the networks that arrange transportation, facilitate medical help and provide other types of assistance. As doing all these constitutes participation in addressing collective concerns over the issue of the war, *Telegram also is an actor involved both in mounting resistance to the authoritarian state and in extending the aggressive expansionist politics of the very same state*. Its political role, consequently, is highly ambivalent, and what exactly networks that involve it end up being capable of doing (or, in other terms, what Telegram “affords”) is co-shaped by the app and its users, all interacting in specific situations. This theoretical understanding of Telegram’s ambivalence can be taken as heuristics for thinking about the political role of other digital media in other situations.

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### Data Availability

To protect research participants’ identities, data will not be made available.

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## About the Author



**Olga Zvonareva** is an assistant professor at the Department of Health, Ethics and Society, Maastricht University, the Netherlands. Situated in the field of science and technology studies, her primary research line concerns relations between scientific knowledge, technologies, and politics. She is especially invested in studying instances of participation in situations when members of the public are discouraged from doing so.

# Fleshing Out the Invisible: Activating Social Empathy Through the Material

Maria Loftus  and Fiona Murphy 

School of Applied Language and Intercultural Studies, Dublin City University, Ireland

**Correspondence:** Maria Loftus ([maria.loftus@dcu.ie](mailto:maria.loftus@dcu.ie))

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## Abstract

This article begins with the material—objects that hold stories, reveal histories, and provoke sensibilities. *Ordinary Treasures: Objects From Home* is a short film that foregrounds these materialities as a form of everyday activism (Chatterton & Pickerill, 2010), tracing how displaced individuals become visible through what they hold dear. In this cinematic work, international protection applicants and refugees craft an evocative narrative around the singular object each brought from home, invoking “thick solidarity” (Liu & Shange, 2018; Maillot et al., 2023). It is the material—small, mundane, yet profoundly resonant—that animates these narratives and disrupts the apparent divide between what is visible and what is not. The film’s anonymous participants emerge in fragments: hands in motion, shadows cast, voices layering against a backdrop of an original score that samples their stories. This fragmented presence centres both the material and the relationality at its core, revealing the co-presence of the visible and the unseen, of the tangible and the unspoken. Motivated by rising anti-immigrant rhetoric in Ireland (Vieten & Poynting, 2022), the film seeks to cultivate “relationships of discomfort” (Boudreau Morris, 2016), unsettling the frames of ignorance and challenging the boundary work of exclusion. This article aims to examine the materialities evoked by the film, the processes of their cinematic articulation, and their impact on audiences. Anchored in shared imaginings, co-creation, and a desire to foster social empathy, *Ordinary Treasures* becomes an uneasy yet vital form of solidarity (Roediger, 2016). It stands as a creative interruption, offering an alternative vision of everyday activism in an Ireland grappling with the rise of populism. In this article, we will trace how these materialities themselves give rise to theoretical frameworks, shaping and reshaping our understanding of their entanglements. These are not static systems but emergent dynamics, unsettling assumptions and holding space for new solidarities to form.

## Keywords

celebrating the ordinary; co-design; materiality of displacement; participatory filmmaking; thick solidarity

## 1. Introduction

This article offers an analytical reflection on the materiality of displacement as revealed in the co-created short film *Ordinary Treasures: Objects From Home*. At its core, this work emerges not only as a form of academic activism but as an insistence on the tangled, enduring relationships between bodies, places, and things—relationships that continue to exert force even after rupture and dislocation (Schradié, 2018). Here, the aim is not to delve into participatory filmmaking as a practice in itself but rather to trace how the film makes visible the materialities that anchor the forcibly displaced, urging us to rethink what it means to inhabit, to belong, to endure.

*Ordinary Treasures* embodies what Liu and Shange (2018) describe as “thick solidarity”—a solidarity forged not in grand proclamations but in the small, intimate gestures of care embedded in the everyday (Chatterton & Pickerill, 2010). The film unfolds over ten minutes, structured around a single evocative question: “What did you bring with you when you fled your home?” This question, deceptively simple, slices through the abstractions of policy and bureaucratic discourse, revealing the tangled material and emotional realities of forced displacement (Maillot et al., 2023).

Six participants, all members of the DCU Irish Refugee Integration Network, share their stories through the objects they carried with them on their journeys. We workshoped the film over six workshops from February to April 2023 with the shoot taking place in early May of that year. A bloodstained Nicaraguan flag evokes both the resistance and the loss that shaped its owner’s departure. A Tibetan sound bowl, carried from Ukraine, resonates with the longing for peace and healing. Scuffed dance shoes remember the rhythms of a lost home, while a coat holds the warmth of familial memory. Two precious necklaces, rarely taken off, served as shields against harm and a tether to loved ones left behind. These objects, far from mere symbols, are material archives—memory in tangible form, bearing witness to lives disrupted and held together.

Five of the participants chose to remain anonymous, their voices and stories foregrounded while their identities were carefully protected. The visuals, in turn, focus on the storied objects, allowing their materiality to evoke the profound resonances of their owners’ experiences. One participant chose full visibility, his story delivered with a clarity and determination that invites radical empathy. This interplay of presence and absence—of visibility and veiling—highlights the tension between precarity and agency that shapes storytelling for those navigating forced displacement (Bloemraad & Menjívar, 2022).

This dynamic raises key questions central to this article: How does *Ordinary Treasures* make visible the materialities of displacement, and in what ways do these materialities work to reconfigure public understandings of forcibly displaced experiences beyond abstraction and objectification? Furthermore, how does the participatory filmmaking process itself cultivate social empathy, challenging audiences to engage with displacement as an embodied, ongoing reality? What does it mean to use creative co-design to shift narratives and invite viewers into a form of “thick solidarity” that recognises not only the humanity but also the political agency of those so often rendered invisible?

To approach these questions, we take the objects as entry points, following their trajectories in the spirit of de Laet and Mol’s (2000) invitation to “follow the objects.” These storied artefacts are not static markers of loss but active agents within complex relational networks, generating meanings that exceed mere



representation. Through these material presences, *Ordinary Treasures* challenges the notion of displacement as absence, revealing instead its ongoing reassembly of fragments into new, precarious, yet resolute forms of being.

This article, like the film it discusses, is intended for a broad audience and aims to contribute to public and policy debates by exploring the material aspects of forcibly displaced life. The focus on these objects and their resonance offers a way of connecting the intimate and the systemic, suggesting how holding onto these items can reflect an effort to preserve a sense of self and maintain visibility. This attunement to the material provides a lens to understand how forcibly displaced individuals navigate their experiences of dislocation and exclusion, expressing a sense of belonging in often challenging circumstances.

The discussion begins by situating the film within the broader rise of populism and anti-immigrant rhetoric in Ireland (Vieten & Poynting, 2022), contextualising the urgency of this creative intervention. We then explore how the film enacts this intervention, not through narratives of victimhood but through the presence of matter—how objects, bodies, and voices coalesce to produce a different sense of forcibly displaced experience. By employing the lenses of physicality, the sensory, and the affective, we elucidate how these materialities are made to matter, how they resonate beyond the screen and into public consciousness. This project, then, is an enactment of “thick solidarity” (Liu & Shange, 2018)—uneasy, fragmentary, yet deeply committed to unsettling the narratives that seek to confine and reduce forcibly displaced lives.

Through its focus on the materialities carried by the forcibly displaced, *Ordinary Treasures* disrupts the exclusionary and hostile narratives that dominate populist discourse. It foregrounds complexity and presence, emphasising the tangible as a means of holding together identities fractured by dislocation. This work calls for a reimagining of solidarity—one rooted in material engagement, unsettling comfort, demanding recognition, and compelling us to stay with the difficult, yet necessary, work of connection.

## 2. Social Empathy Through Participatory Film

The rise of far-right hate in Ireland, as elsewhere, draws its strength from the fractures and anxieties sown by decades of neoliberal austerity and the erosion of social safety nets (Cannon et al., 2022). Across Europe and beyond, far-right movements have adeptly harnessed cultural anxieties and economic grievances, reframing complex systemic failures into simplistic narratives of blame and exclusion. In Ireland, a country long defined by its diasporic history, this resurgence of nativism is particularly jarring. Anti-immigrant demonstrations are becoming more frequent, and incendiary rhetoric finds fertile ground in communities grappling with housing crises and stretched public services (Connell & O’Carroll, 2023). These grievances, instead of being addressed through systemic change, are weaponised by far-right actors, targeting asylum seekers and migrants as scapegoats (Perry & Scrivens, 2016). The arson attacks on asylum centres stand as chilling manifestations of this hostility (McCarron et al., 2024).

Such tactics thrive within the contours of what Fisher (2022) termed capitalist realism: a pervasive sense that no alternatives to the current socio-economic order exist. The far-right exploits this landscape, offering exclusionary myths as solace and redirecting anger away from the structural conditions that breed insecurity (Gallagher et al., 2023). These myths do not simply fill a void; they actively reshape social imaginaries, transmuting structural despair into reactionary fervour. In this cycle, affective economies of loss and



grievance are weaponised, not to challenge the conditions of abandonment but to entrench them further, recasting precarity as the fault of an Other rather than the logic of capital itself. What emerges is not merely ideological capture but a material investment in the reproduction of dispossession—a recursive loop in which suffering finds its release in punitive rather than emancipatory desires.

In this context, empathy becomes a radical, even subversive act—a deliberate refusal to accept the divisions dictated by capitalist and nationalist logics. As academics in a school of languages and intercultural studies and active members of the DCU Irish Refugee Integration Network, our commitment to solidarity is not theoretical but deeply entwined with our daily work, echoing Connell's (2019) vision of what a university can aspire to be. Through teaching English to international protection applicants and refugees, we have witnessed firsthand the resilience and courage of our students, who bring their stories and hopes into the classroom even amidst profound uncertainty. When far-right protests began to erupt in Dublin, our students shared with us their fears—of being targeted, of being made invisible, of having their humanity questioned. These conversations sharpened our resolve to respond together, collaboratively, through a medium that could amplify their voices and centre their lived experiences.

Our film, *Ordinary Treasures*, thus begins with refusal: a refusal to let dehumanisation and fear shape the narrative of forced displacement. Against the erasures wrought by far-right discourses, it centres the material and intimate stories of the forcibly displaced—those who navigate the liminalities of asylum, their voices too often silenced in national debates. Through the objects they carried—a bloodstained flag, a Tibetan sound bowl, shoes worn to dance, a coat imbued with familial warmth—the film renders visible the entangled threads of memory, loss, and hope that these materialities hold.

In engaging with these storied objects, *Ordinary Treasures* does more than recount individual journeys; it unsettles the structures that drive displacement and division. The film does not merely evoke empathy but reconfigures it, activating a social empathy that insists on the shared vulnerabilities and interdependencies obscured by the isolating logics of neoliberalism (Briciu, 2020; Couldry, 2010; Silke et al., 2021). It gestures towards an alternative politics—one grounded in thick solidarity, where the intimate and the systemic converge to reimagine belonging, care, and collective futures.

Social empathy, as envisioned in our short film, seeks to move beyond the surface act of emotionally identifying with another. It aims to provoke an awakening—a deeper recognition that our lives are fundamentally intertwined with those whose experiences are systematically marginalised and whose voices are often silenced by dominant narratives (Keen, 2006). This form of empathy is not about pity or condescension but about acknowledging and engaging with the relational entanglements that bind us all. As Dolan (2017) articulates, such empathy is essential for forging meaningful connections across divides, grounded in an understanding of our shared human condition and mutual vulnerabilities.

The film insists on reconstituting relationships between bodies, places, and things, focusing on the material traces of displaced lives as provocations that confront and unsettle what we take for granted as familiar. These objects—loaded with memory, loss, and hope—become conduits for rethinking relationality. They demand an active, embodied engagement from the audience, challenging the abstractions and objectifications that reduce the forcibly displaced to statistics or threats.

By foregrounding these storied materialities, the film invites viewers to see the forcibly displaced not as distant “others” but as subjects whose lived realities expose and speak back to the cultural logics of erasure and exclusion. Social empathy, in this context, is not static but generative—it reframes how we perceive, relate to, and act within a world shaped by displacement. It calls for a reckoning with our complicity in the systems that perpetuate these conditions while opening space for collective reimagination, where solidarity is not simply acknowledged but actively cultivated.

Building on the call for social empathy, participatory filmmaking has been a vital methodology for making the complex narratives of displacement visible and legible to wider publics. In *Ordinary Treasures*, we use participatory film to not only evoke empathy but to foster solidarity—positioning those often portrayed as passive subjects of discourse into active roles of representation (Lenette, 2019). This method challenges the erasures and objectifications that displacement narratives are often subject to, enabling participants to reclaim agency in how their stories are told.

As Roy et al. (2020) argue, participatory filmmaking shifts the practice from simply documenting lives to co-creating stories, opening space for more nuanced and relational understandings. Similarly, Frisina and Muresu (2018) describe this co-creation as an act of political solidarity, one that foregrounds the agency of participants and disrupts traditional hierarchies between filmmaker and subject. *Ordinary Treasures* resists the tendency to render participants as mere symbols of suffering, instead presenting them as active political subjects whose material lives carry weight and meaning.

Practically, this participatory ethos shaped every stage of the filmmaking process. The six participants were involved from the concept stage, working with a scriptwriter to refine their narratives and collaboratively shaping the visual and thematic direction of the film, attempting to adhere closely to participatory design principles (Robertson & Simonsen, 2013). Through iterative storyboarding sessions, participants reworked their stories and made decisions about how their objects—and their own presences—would be framed. Their contributions extended to the cinematography, where participants guided choices such as camera angles and the treatment of their artefacts, ensuring the visuals aligned with their visions. Even in post-production, agency was centred, with participants providing feedback on edits and adjustments, fostering a process that was as inclusive and democratic as possible.

The role of the activist academic is also deeply entangled with this work—operating within and against the neoliberal university while striving for social justice. Academic freedom is increasingly constrained by market-driven imperatives, and the rise of far-right hostility adds further challenges. Yet, even within these constraints, activist academics are uniquely positioned to leverage their platforms to engage in public discourse, resist regressive policies, and advocate for marginalised communities. Social empathy thus becomes integral to activist academia. It shapes not only the research questions we ask but also how we engage with communities and the methodologies we employ. This is about fostering solidarities that are not just analytical or theoretical but felt, embodied, and uncomfortable (Boudreau Morris, 2016; Roediger, 2016).

Our work thus aligns with the ethos of an “engaged anthropology” that foregrounds care, slowness, and horizontal participation (Rasch et al., 2022), employing participatory filmmaking to foster public engagement and activate social empathy. In this sense, *Ordinary Treasures* disrupts the extractivist tendencies of

traditional academic work—shifting away from the model of knowledge extraction and instead co-creating spaces where shared vulnerabilities are made visible. Participatory filmmaking, as employed in *Ordinary Treasures*, becomes a tool to counter the narratives of capitalist realism and far-right populism, insisting that the stories of the forcibly displaced are not only heard but felt (Roy et al., 2020).

This article thus champions the use of participatory filmmaking as a tool for activist academia. Through *Ordinary Treasures*, we seek to illustrate how film can transcend traditional academic boundaries, fostering a more inclusive space for public interaction and societal change (Roy et al., 2020). By dissecting the participatory process, we argue for the transformative potential of such filmmaking in countering narratives of exclusion and fostering an engaged, empathetic public discourse in an era marked by division and hostility. Social empathy, in this context, is not merely a rhetorical flourish but a political necessity—a means to re-imagine our entanglements and recognise the deeply relational nature of the social world, insisting on a collective presence even amidst dislocation.

### 3. The Methodology of Co-Design and the Materiality of Displacement

Method is never neutral. It organises relations, structures authority, and dictates the conditions under which knowledge is produced and circulated. In *Ordinary Treasures: Objects From Home*, co-design is not simply a technique but a political stance—an insistence on care, slowness, and collaboration as forms of resistance against extractive research practices (Bardzell & Bardzell, 2011; Mountz et al., 2015). This methodology does not seek to capture or translate experience but to create space for participation on participants' own terms, foregrounding ethical entanglements rather than claiming to resolve them.

At the core of this approach is a commitment to participants—international protection applicants and refugees—whose lived experiences do not serve as raw material for academic inquiry but as structuring forces that shape the project itself. Anonymity was not treated as a mere procedural safeguard but as an active decision, a negotiation of visibility in a world where forced displacement renders exposure risky. Consent was not a one-time formality but an ongoing process, ensuring that participation did not come at the cost of security or dignity. To co-design under these conditions is to recognise that voice is not freely given, nor always desired—it is shaped, constrained, and sometimes deliberately withheld. The task, then, is not simply to foster social empathy but to remain accountable to the structures that determine who gets to speak, who remains unseen, and under what conditions participation itself becomes possible.

Throughout the co-design process, we remained acutely aware of the urgency of fostering social empathy, particularly in a climate where anti-immigrant sentiment is gaining ground. This awareness was not incidental but foundational, shaping everything from our methodological choices to the film's thematic structure (Murphy & Loftus, 2023). Rather than relying on abstraction or moral appeals, we turned to the material—objects that anchor lives, hold histories, and traverse borders. The universality of material culture became a bridge, a way to draw audiences into the complexities of displacement not through spectacle, but through recognition.

People form attachments to things; they imbue them with meaning, memory, and a sense of home. By inviting participants to share the objects they carried when forced to leave their countries, we were not only eliciting personal narratives but unsettling the assumed distance between *them* and *us*. These objects, small yet potent,

made visible the intimate, textured realities of forced migration—offering not just testimony but an invitation for audiences to locate themselves within these entangled histories of loss, survival, and belonging.

These materialities—objects as extensions of memory and identity (Miller, 2010)—did not merely serve as narrative devices but as conduits of affect, drawing participants into an act of self-inscription that was both deeply personal and inherently relational. If material culture became the bridge between audience and participant, it also structured the collaborative process itself, forging unexpected intimacies and solidarities. Participants navigated the delicate interplay between visibility and protection, shaping their narratives in ways that honoured both their agency and their right to opacity.

Co-creation was never just a methodological choice but a means of recalibrating the usual dynamics of representation—ensuring that storytelling was not something done *to* participants but something crafted *with* them. In this space of negotiated authorship, new forms of connection emerged, not only between participants but within the project team itself. This was not empathy as distant recognition but as entanglement—an active engagement with the precarities and possibilities of storytelling in a world where displacement too often reduces people to abstractions.

The performative element of the film took shape as participants rehearsed and recorded their stories, emphasising inclusivity, respect, and shared authority (Sarria-Sanz et al., 2022). As directors, our role was to facilitate rather than dictate—to manage power dynamics so that participants could genuinely co-create their representations. This participatory approach turned filmmaking into an act of solidarity, foregrounding participant agency and transforming storytelling into a shared act of meaning-making (Roy et al., 2020).

A critical moment came when participants resisted the suggestion to align their stories with places of historical conflict in Ireland. Instead, they chose settings that symbolised vitality and hope—parks, beaches, bustling streets—asserting their desire for a narrative that conveyed optimism. This decision reshaped the thematic focus of the film, actively countering the dominant discourses that frame displacement in terms of loss and suffering. Here, the participants shaped not only the content but also the affective tone of the film, challenging traditional narratives of victimhood and invoking instead a forward-looking energy.

We believe that participatory filmmaking in *Ordinary Treasures* has the potential to activate social empathy by making the materialities of displacement speak. These objects became more than symbols; they were nodes in a web of relations—connections that extended beyond the individual to encompass shared histories and future possibilities. By involving participants as co-creators, we disrupted the boundaries between filmmaker and subject, inviting audiences to see these lives not as distant or abstract, but as entangled with their own (Roy et al., 2020). In doing so, the film confronts the capitalist logic of separation, insisting instead on a shared vulnerability—a solidarity that transcends borders and categories.

The significance of material culture in migration research, as explored by Yi-Neumann et al. (2022) and Miller (2010), provides a theoretical foundation that resonates deeply with our project. Their work critiques the reduction of migrant experiences to “bare life,” instead emphasising the rich, complex relationships between people and objects that persist even under conditions of forced displacement. Objects are not passive remnants but are active participants in shaping emotions, fostering belonging, and facilitating place-making. In *Ordinary Treasures*, the objects carried by displaced individuals are imbued with deep emotional, historical,

and social significance. These personal artefacts become anchors amidst the turbulence of displacement, offering continuity and a sense of belonging that resists the erasure so often imposed by forced migration. This entanglement of methodology and materiality embodies our commitment to participatory filmmaking as a practice of activist scholarship. Here, material culture is not merely a passive setting but an active force—co-constructing and mediating identities and memories in states of flux and transformation.

#### 4. Framing as a Technique for Activating Social Empathy

In the words of Donna Haraway, “it matters what stories tell stories....It matters what worlds world worlds.” Framing lies at the heart of how stories are told and understood (Entman, 1993). It shapes the contours of empathy, determining what resonates, what moves, and what remains opaque. In the context of *Ordinary Treasures: Objects From Home*, framing was not merely a stylistic choice but an intentional strategy for challenging the pervasive narratives of victimhood and exclusion that often define the discourse around forced displacement. By deliberately framing the stories of participants in ways that highlighted agency, resilience, and shared material culture, the film sought to cultivate social empathy—an empathy that invites the audience to see themselves as implicated in the lives of others.

Framing, as Goffman (1974) discusses, is an operation of power—an act of selection and emphasis that dictates not just what is seen but how it is seen, rendering certain narratives legible while foreclosing others. Within the dominant regimes of perception, forcibly displaced individuals are flattened into figures of helplessness or threat, their agency obscured by the humanitarian-industrial complex’s compulsion to categorise, manage, and contain. Our project resisted these reductive frames, foregrounding instead the materialities that individuals carried with them—objects imbued with personal, cultural, and emotional significance. These were not mere possessions but inscriptions of endurance, small acts of self-worlding that exceed the logics of displacement and dispossession. In centring these material traces, we sought not to universalise suffering but to reveal the uneasy intimacies of forced displacement—the ways in which survival is tethered to objects that persist even when borders are redrawn and lives are fractured.

Solmaz Sharif’s *Dear Aleph* articulates this entanglement of state violence, abandonment, and the aesthetics of suffering:

You’re correct. Every nation hates its children. This is a requirement of statehood. This and empathy. Empathy means laying yourself down in someone else’s chalklines and snapping a photo. (Sharif, 2016)

Sharif’s provocation unsettles the presumed ethics of witnessing, forcing us to ask: what does it mean to look at another’s suffering? What does it mean to document it? In the circuits of humanitarian and journalistic representation, suffering is often rendered into spectacle—an image captured, circulated, and consumed. But what if, instead of the image, we traced the material residues of displacement, the objects that refuse to conform to the logics of victimhood, and the silent acts of world-making that persist beneath the gaze of the state?

Social empathy, as Dolan (2017) suggests, is not merely an exercise in feeling another’s pain; it is an ethical and political demand to recognise the conditions that structure that pain—to apprehend not just suffering but the architectures that produce and sustain it. But here lies the rub: empathy, as it is often mobilised, risks

collapsing into sentimentality, a fleeting affective response that displaces rather than deepens responsibility. Through our film, we sought to resist this tendency, using the framing of personal objects not simply to generate emotion but to unsettle the audience's sense of distance, to pull them into the uneasy proximities of shared vulnerability. To lay oneself down in another's chalklines, as Solmaz Sharif compels us to consider, is not just an act of imaginative substitution—it is an exposure, a confrontation with the ways in which the traces of displacement, violence, and abandonment are not only witnessed but inhabited. Our framing insists that empathy cannot end at affective recognition; it must extend into an awareness of how one's own positioning is enmeshed within these structures of vulnerability and resilience. It is not about seeing oneself in the Other, but about recognising the conditions that make such distinctions possible in the first place, about tracing the material and discursive formations that render some lives precarious while others remain secure. To do otherwise would be to reproduce the very logics of dispossession that empathy, at its best, seeks to challenge.

Empathy, as an analytic category, is not without its complications. Scholars such as Bloom (2016) caution against the potential of empathy to lapse into spectacle, a mechanism through which suffering is consumed rather than confronted—an affective circuit that permits audiences to *feel* another's pain while absolving them of any obligation to act. Ponzanesi (2016) similarly warns of the depoliticisation that occurs when empathy is framed as an end in itself rather than a site of political reckoning. In *Ordinary Treasures*, we sought to resist these pitfalls, rejecting sentimental narratives that flatten suffering into affective currency and instead insisting on a framing that demands both recognition and response.

By foregrounding everyday objects, we anchored experience in the material, resisting the gravitational pull of abstraction and disembodiment. These objects—fragments of home, traces of lives interrupted—were not mere props but conduits of history, struggle, and endurance. They refused the voyeuristic gaze that too often accompanies narratives of displacement, instead insisting on the particularity of lived experience, on the weight of the material in the shaping of memory and survival. If empathy is to hold any transformative potential, it must move beyond the momentary flicker of identification; it must become a confrontation with the structures that render some lives precarious while securing others, a demand to reckon with complicity, proximity, and the politics of care.

Pooja Rangan's critique of participatory documentary in *Immediations: The Humanitarian Impulse in Documentary* (Rangan, 2017) further exposes the limits of this framework, revealing the ways in which participatory approaches often operate as ideological sleights of hand. The rhetoric of "giving a voice to the voiceless" risks obscuring the fundamental power asymmetries at play, offering the illusion of agency while retaining control over whose voices are heard, how they are framed, and to what ends. Even when marginalised individuals are invited to speak, their participation remains constrained by the very structures that claim to centre them; the terms of engagement—set by the filmmakers—often delimit their capacity to shape the narrative in any substantive way.

This critique is central to our project, which, despite its participatory aspirations, was not exempt from these tensions. The participatory element in *Ordinary Treasures* was necessarily bounded; while participants influenced aspects of the framing, the broader parameters of their involvement—what could be included, what could be left unsaid—remained, as Rangan highlights, ultimately dictated by the researchers. Editorial control and the final cut rested with us, underscoring the inescapable tension between inclusion and

authority. Yet, rather than treating this as an ethical failure to be mitigated, we approached it as a site of necessary reckoning—a recognition that participation, too, is always structured by histories of exclusion and control. Our aim was not to dissolve these asymmetries but to make them legible, to hold space for the contradictions inherent in collaborative storytelling, and to interrogate how such projects might move beyond the fantasy of participatory purity toward a more honest engagement with the politics of representation.

The techniques of framing in *Ordinary Treasures* were designed not merely to elicit empathy but to provoke an encounter—one that is transformative rather than extractive, unsettling rather than affirming. By involving participants in shaping their own narratives—choosing settings, determining angles, guiding the flow of their stories—we attempted to shift the balance of representation, resisting the voyeuristic impulse that so often accompanies visual storytelling on displacement. This approach sought to recognise participants as co-creators rather than subjects, their agency not an afterthought but a structuring principle. Yet the critique persists: Does this form of co-creation truly rupture the embedded hierarchies of authorship, or does it risk becoming, as Rangan (2017) warns, an act of *immediation*—a sleight of hand that presents the illusion of unmediated authenticity while power imbalances remain intact?

Framing, then, is never neutral; it is always an ethical and political practice. It determines not only what is seen but how it is seen, how relations of power are made visible—or obscured. In participatory filmmaking, framing is not simply about storytelling but about structuring the conditions of recognition, about demanding more than passive viewership. In an era where far-right rhetoric mobilises its own framing strategies to dehumanise, exclude, and fracture solidarity, counter-framing must do more than bear witness; it must refuse the seductions of sentimentality and instead insist on complicity, on the ways in which all of us are bound—materially, historically, and affectively—to the lives of those we are called upon to empathise with. The challenge is not just to represent displacement differently, but to rupture the conditions that render displacement a chronic and inevitable feature of the present. Empathy, in this sense, can only be political—an embodied reckoning with the entanglements of responsibility, recognition, and action.

## 5. Resonance and Withdrawal: Crafting Audience Engagement

Framing is never just a technical choice; it is an ideological act, a structuring of perception that determines not only what is seen but how it is encountered. In *Ordinary Treasures: Objects From Home*, participatory filmmaking offered a method—but also a provocation. How to resist the gravitational pull of the humanitarian gaze, that familiar choreography in which marginalised voices are included only to serve a pre-determined narrative, their presence legitimating the benevolent spectatorship of an audience that remains untouched?

Rangan (2017) critiques this dynamic, arguing that participatory documentaries often fail to disrupt the fundamental asymmetries between filmmaker, participant, and audience. Instead of redistributing agency, they risk turning experience into a consumable fragment—something to be *witnessed* rather than reckoned with. The challenge, then, is not simply to widen the frame but to interrogate its very conditions: Who speaks? Under what terms? And to what end?

In response, our project sought not only to reframe the narratives of forced displacement but also to explore the deeper affective processes of resonance and withdrawal. These concepts underpin how the audience is invited to connect with the film and engage with its message. Resonance, as articulated by Rosa (2019), is



more than an emotional echo; it is an active relationship between self and world, a space where both are transformed through their encounter. Resonance allows us to transcend superficial emotional identification, fostering a deeper, reciprocal engagement.

The personal objects presented in the film act as vessels of this resonance—items that carry memories, attachments, and hopes across borders. They provide a tactile, visual link to the lives of the displaced, inviting audiences to connect with them not as distant strangers but as fellow human beings who share similar attachments and emotions. The emphasis on everyday objects was intentional; it drew on the universality of material culture to evoke empathy while avoiding the spectacle of suffering that Rangan warns against. Resonance in this context is characterised by the unpredictability of genuine connection—moments when viewers encounter an emotional truth that feels both familiar and disarming. Such resonance has, in many instances, led to action, with audience members inspired to volunteer or engage with refugee issues beyond the confines of the screening room.

Where resonance invites intimacy, withdrawal makes space for distance. In *Ordinary Treasures*, withdrawal is employed as a strategic narrative device—a conscious withholding, a space that allows for privacy and agency on the part of the participants. Drawing on Hesselberth and de Bloois' (2020) politics of withdrawal, this approach is not a passive retreat but an active reconfiguration of the narrative space. By deliberately limiting what is shared, participants reclaim narrative power, maintaining control over their stories and ensuring their representation does not descend into voyeurism or exploitative empathy.

Withdrawal also serves as a critique of the conventional expectation that participatory projects should offer unmediated access. It insists on the dignity of refusal—the right of displaced individuals not to become entirely knowable to the audience. This serves as a powerful counterbalance to resonance, challenging audiences to confront the limits of their understanding and to reflect on the ethical complexities of empathetic engagement. As Rangan (2017) suggests, the imperative in participatory media is not only to provide visibility but also to interrogate the power structures underpinning that visibility. By utilising withdrawal, we sought to retain the integrity of participants' experiences while prompting viewers to consider what remains unsaid, absent, or inaccessible.

Resonance and withdrawal work together to shape the audience's experience of *Ordinary Treasures*. They cultivate a form of social empathy that goes beyond superficial emotional connection, encouraging a more thoughtful and ethical engagement with the lived experiences of displaced individuals. This approach moves the audience from passive spectatorship to a more engaged and ethically aware form of involvement—one where empathy is not just about feeling, but also about inciting responsibility.

Our screenings have demonstrated that this balance—between inviting connection and maintaining respectful distance—can provoke meaningful change. Audience members, varying from members of the university community, trainee teachers, second chance learners to grassroots activists, have not only reported feeling a deep emotional connection to the stories but have also taken steps towards engagement, such as some student viewers volunteering in refugee support efforts such as English teaching and community garden work. In this way, the film's resonance does not dissipate into passive sentimentality; it echoes in the actions taken by those who have experienced it.

This intertwining of resonance and withdrawal, following our deliberate framing strategy, is designed to foster an ethical, reciprocal, and transformative engagement with stories of displacement. It invites the audience into a relational space that insists on responsibility, on understanding the limitations of empathy, and on recognising the shared structures of vulnerability and resilience that connect us all.

## 6. Invisibility, Voice, and the Politics of Social Empathy

Visibility is never just a condition; it is a negotiation, a terrain of power where exposure and recognition are entangled with risk. *Ordinary Treasures: Objects From Home* does not assume that to be seen is necessarily to be freed, nor that to remain unseen is to be erased. In contexts of forced displacement, visibility can mean advocacy, but it can also mean surveillance, categorisation, or co-optation. The film does not seek to make everything legible but instead asks how voice moves—how it emerges, recedes, and sometimes deliberately withdraws.

Rangan (2017) reminds us that visibility is not inherently emancipatory; it can just as easily be a means of capture as it can be a tool of resistance. Not all who are seen gain agency, and not all who remain unseen are without it. *Ordinary Treasures* navigates this complexity by refusing the easy equation of visibility with power, recognising that voice does not always announce itself loudly. Sometimes it takes shape in fragments, in objects, in silences that resist translation. Social empathy, then, is not about making the unseen visible, but about attending to the ways in which presence and absence are structured—who speaks, who listens, and under what conditions recognition becomes possible.

To speak is never just to vocalise; it is to assert presence, to make a claim on the world. But that claim is not always recognised, not always granted the status of legitimacy. *Ordinary Treasures* does not seek to *give* voice—a paternalistic gesture that presumes silence where there is none—but to create the conditions where voices, long present, can emerge on their own terms. Voice is not a gift bestowed but an assertion of being, shaped by histories of recognition and refusal, by the right to be heard and the right to withhold.

These voices do not draw power from the spectacle of being seen. Their force lies in the ability to dictate *when* and *how* to speak, or whether to speak at all. In this sense, voice is not a guarantee of presence but an act of resistance—a disruption of the expectation that visibility equals power. To speak under conditions not of one's choosing is another form of subjugation. To craft the terms of one's own visibility, to determine the context of one's own speech—that is where the radical potential of voice resides.

If voice is an assertion of being, then so too is the choice to remain unseen. Invisibility is not absence, not silence, but a recalibration of power—a refusal to be made legible on someone else's terms. To be seen is not always to be safe; visibility, particularly in contexts of forced displacement, too often becomes a mechanism of exposure, a condition that invites surveillance, policing, and stigmatisation. *Ordinary Treasures* does not treat anonymity as a void, as something to be filled, but as a deliberate act, a strategic negotiation of presence and withdrawal.

This negotiation is starkly evident in the film, where five of the six participants chose to remain anonymous—a decision that speaks not to reluctance, but to the realities of life in Ireland, where the forcibly displaced and migrants generally navigate an increasingly hostile public discourse. Visibility, in such a climate, is never

neutral; it carries risk, it demands justification, it can be weaponised against those who seek recognition on their own terms. As one scholar observes, “acting visibly as a group is itself fraught with risk, as the demand for recognition can easily tip over into stigmatisation and persecution” (Alloa, 2023, p. 326). Within this landscape, invisibility becomes a means of asserting control, not a failure to participate but a refusal to be consumed by a system that too often renders the displaced as either victims or threats. In this way, *Ordinary Treasures* resists the coercive politics of recognition, refusing to equate participation with hypervisibility, and instead centring the right to opacity, to strategic withdrawal, to exist outside the logics of capture.

Meizel’s (2020) concept of multivocality deepens this understanding of invisibility and voice. Meizel describes multivocality as an act of “border crossing”—an engagement with overlapping and intersecting identities, which are shaped by race, ethnicity, gender, and religion. In *Ordinary Treasures*, participants navigate these crossings while choosing strategic invisibility. Their voices are not less powerful for being anonymised; they are resonant because they traverse both the personal and the collective, embodying a transnational story of displacement. The anonymity does not diminish the political weight of their voices; rather, it reinforces their agency, offering a powerful alternative to the visible subject as the primary locus of political action.

The interplay between invisibility and voice is therefore not only visual but also deeply auditory, embodied in the film’s musical composition. The original score was crafted to echo the participants’ vocal expressions, with each voice shaping the music that accompanied it. The owner of the shoes that dance sings in this short film. Her voice, initially fragile, carried the weight of loss—of family, of home. As she sang for us repeatedly, her voice grew braver, stronger, more present, and we re-recorded. Her voice ultimately found its place within the musical score, blending with the simple, resonant tone of a Tibetan sound bowl, both in C Sharp—a distant but resonant key to the rest of the score. The music, created from pitch tracking and analysis of each participant’s voice, captures not only their speech but their emotions, shaping harmony that reflects shared experience.

The film’s score is not simply an accompaniment; it is an extension of the participants’ expressions. It aligns with pitch, timbre, and tempo—core elements of voice prosody—that embody the lived experience of displacement. The score thus stands as a melodic manifestation of thick solidarity, where voice and music intertwine to express not just loss but resilience, not just invisibility but the power of choosing one’s presence. The result is a score that supports the voices it accompanies, allowing them to fill the auditory space, to be heard even in anonymity.

This nuanced interplay between invisibility and voice is integral to activating social empathy in the audience. By framing anonymity as a deliberate choice, *Ordinary Treasures* encourages audiences to think about displacement outside the frames of victimhood and spectacle. It pushes viewers to understand that invisibility is not silence; it is a deeply political act of protection and self-definition. Here, social empathy is invoked not just through what is expressed, but also through what is withheld—the deliberate gaps, the unsaid, and the unshown.

Ultimately, *Ordinary Treasures* illustrates how invisibility and voice intersect to form a potent site of resistance, where the act of being unseen is as politically charged as the act of speaking. The film embodies the frameworks of Palumbo-Liu (2021) and Meizel (2020) while challenging audiences to interrogate the conditions under which visibility becomes a demand and to rethink empathy not merely as emotional resonance but as a recognition of the structures that compel invisibility. It is this form of empathy—one that

does not insist on exposure but instead respects the complexity of choosing when to appear—that the film strives to foster, urging the audience to confront their own positions within the dynamics of seeing and being seen, hearing and being heard.

## 7. Conclusion

What does it mean to *feel* across the distances imposed by borders, bureaucracies, and histories of exclusion? What does it mean to engage not just with stories of displacement but with the material traces of lives uprooted and reassembled? This article has explored the entanglement of material objects, participatory filmmaking, and the materiality of displacement as sites where social empathy is not simply evoked but actively negotiated. Objects do not speak in the way bodies do, but they carry histories, affective charges, and silent demands for recognition—insisting on presence even when voices are disregarded or unheard.

At the centre of this inquiry is *Ordinary Treasures: Objects From Home*, a short film that moves between everyday activism (Mansbridge, 2022) and academic inquiry, unsettling entrenched narratives of displacement and reconfiguring how international protection applicants (IPAs) and refugees are framed. More than an attempt to “humanize” those so often reduced to statistics or political abstractions, the film foregrounds the agency embedded in materiality itself—the way objects carry, conceal, and make visible histories of belonging and loss. It is in this interplay, between what is held and what is withheld, that the possibility of social empathy emerges—not as a passive recognition of another’s suffering, but as a call to rethink how displacement is perceived, mediated, and responded to.

The objects carried by displaced persons are more than mere artefacts—they are conduits of resonance, infused with the histories of belonging, loss, and survival. These objects provide a tangible, affective link between their experiences and the wider public, transforming perceptions of the displaced from abstract figures into individuals with complex, layered identities. Through these material connections, we hoped to foster social empathy—an empathy that extends beyond mere emotional identification and invites viewers to engage with the broader realities of displacement and resilience. The material artefacts demand a recognition of shared human impulses: to preserve, to protect, to remember.

Central to the film’s creation was a commitment to co-design, embodying what has been referred to as “thick solidarity” (Liu & Shange, 2018). This form of solidarity is not simply abstract; it is rooted in the collective process of storytelling. At a time when anti-immigrant sentiment often pervades public discourse, co-creation serves as a form of academic activism, combining scholarly engagement with public impact. By involving IPAs and refugees in the filmmaking process, we sought to disrupt passive representations of the displaced and position them instead as co-creators with agency and voice.

While the film’s reach has been modest, it has sparked meaningful dialogue where it has been shown. It has prompted audiences to reflect on their own roles and has even inspired some to take action—whether through volunteering or other forms of community support. Such responses highlight the potential of participatory filmmaking to create not only empathy but also engagement and solidarity. However, it is important to acknowledge that these impacts are gradual and contingent, rather than sweeping transformations.

As we reflect on this project, we remain aware of its limitations. Our aim was not to present a finished solution or assume a dramatic shift in social attitudes, but rather to open a space for reflection, shared vulnerability, and the possibility of action. We recognise the complexities and challenges inherent in representing vulnerable populations ethically and strive to remain cautious in any claims about impact.

Our journey continues through new creative mediums, including a graphic novel based on the film, which has received funding through the Irish Research Council's New Foundations grant. This graphic novel will expand our storytelling toolkit, seeking to connect with new audiences through visual narrative. Digital platforms also present new opportunities to extend the reach of this participatory work, although these must be navigated thoughtfully to maintain the integrity of participant voices.

Ultimately, *Ordinary Treasures: Objects From Home* is not an attempt to speak for the displaced, nor to offer visibility as an unexamined good, but to carve out a space where presence—whether articulated, withdrawn, or redefined—remains in the hands of those who inhabit it. In a moment when hostility towards migrants is not only rising but being codified into policy, aesthetics, and public discourse, the task is not simply to give voice, but to rethink the conditions under which voice is heard, who is compelled to speak, and who is granted the right to silence.

To navigate this terrain requires more than sentiment or spectacle; it demands an ongoing reckoning with how stories of displacement are told and by whom. It means recognising invisibility not as absence but as strategy, resonance not as affect but as force. Chosen visibility—when to be seen, when to withdraw, when to refuse the terms of recognition altogether—remains one of the most potent acts of resistance. This is the challenge: to create spaces where voice is not extracted but emerges on its own terms, where empathy is not passive but compels a confrontation with complicity, and where presence is not simply acknowledged but reconfigures the very frameworks that determine whose lives matter in the public imagination.

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## About the Authors



**Maria Loftus** is an assistant professor in French language and French literature and cinema at the School of Applied Language and Intercultural Studies. With a doctoral background in Sub-Saharan African documentary cinema, she embraces any opportunity to bring the multimodal into her teaching and flex her creative muscles. More recently, her research outputs draw on the co-design of anti-racism artefacts and the fostering of social empathy.



**Fiona Murphy** is an anthropologist based in the School of Applied Language and Intercultural Studies. She navigates the deeply human stories of displacement, from the Stolen Generations in Australia to people seeking asylum and refuge in Ireland, the UK, and Turkey. Fiona has a passion for creative and public anthropology—where field notes become art and stories come alive. She's always experimenting with new forms and genres, breathing fresh life into the discipline.



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