

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

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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

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. (in press) 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., in press; 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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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

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