SSM - Qualitative Research in Health 9 (2026) 100692

Contents lists available at ScienceDirect

SSM - Qualitative Research in Health

journal homepage: www.journals.elsevier.com/ssm-qualitative-research-in-health

Do-it-yourself hormones: constructing credible knowledge in an online transgender forum

Natasa Stoli *, Klasien Horstman, Olga Zvonareva

Department of Health, Ethics & Society, CAPHRI School, Maastricht University, the Netherlands

ARTICLE INFO

Keywords:
Citizen science
Patient participation
Qualitative research
DIY pharmaceuticals
Knowledge production
Safety and efficacy
Science and technology studies
Transgender healthcare

ABSTRACT

On the continuum of patient participation between "informed patients'' and "patients in control'', DIY pharmaceuticals are considered the most radical because they are produced outside regular medical professional and regulatory contexts. While some see DIY pharmaceuticals as an important contribution to making pharmaceuticals more accessible, others are concerned because they circumvent established procedures for assessing safety and efficacy. We studied a particular case of DIY pharmaceuticals: citizen drug developers who enable access to hormone therapy in transgender health care through the home production of hormones. By studying an online community of DIY hormone producers, we aimed to gain insight into how they strive to develop knowledge practices that are credible and safe. Theoretically, we drew from science and technology studies scholarship on knowledge credibility and patient participation in knowledge production. We relied on a qualitative study of an online forum to generate our data. The analysis shows how citizen drug developers constructed and performed standards of safety and efficacy in sharing knowledge within their community and how these standards were ensured. DIY pharmaceuticals can be an unconventional but important pathway for citizen participation in biomedical knowledge production, employing strategies for performing credible knowledge outside formal laboratory spaces and in the absence of external supervision.

1. Introduction

In recent decades, there has been a striking shift in the role of patients in medicine. Studies of patient participation (Arksey, 1994; Caron-Flinterman et al., 2005, 2007; Epstein, 1995, 1996; Pols, 2014; Rabeharisoa & Callon, 2002, 2004) show that instead of being viewed as passive recipients of professional knowledge and advice, patients are increasingly considered partners whose feedback is crucial for the provision of healthcare and the development of biomedical knowledge. Patient participation in healthcare and healthcare innovation is being encouraged by governments, regulators, and funders to improve the quality and responsiveness of healthcare systems.

While this change has generally been applauded, some scholars have critically studied the rise of patient participation. Carol-Flinterman et al. (2007) have argued that patients' involvement in biomedical decision-making is largely absent at a structural level, and collaborations between patients and medical professionals often degenerate into tokenism, with the perspectives of the former being overruled by the latter. In line with this, scholars such as Pols (2014) and Boardman (2017) have shown that even in cases where patient participation was promoted, patient knowledge was viewed as less valuable than that of biomedical professionals. Consequently, while patient participation is widely accepted as a normative ideal, in practice, it entails a wide variety of activities, most of which are shaped within organisational contexts where professional medical norms for credible knowledge are operative. One rare example in which patients and their carers do take the lead in biomedical knowledge production, which has been extensively researched by Rabeharisoa and Callon (2002, 2004), is an initiative from the French Muscular Dystrophy Association (l'association française contre les myopathies), commonly referred as AFM.

In our research, we studied a very specific type of participation: DIY (do-it-yourself) pharmaceuticals. In general, the term "DIY" refers to a movement that encompasses a variety of activities, all sharing a common characteristic: individuals making things for themselves, usually at home. Originally, DIY has tended to refer to home improvement projects and tinkering with furniture or electronics (or any similar applicable interest). In recent years, its meaning has greatly expanded to include sectors usually restricted to professional scientists, such as biology and

---

* Corresponding author. Minderbroedersberg 4-6 6211 LK, Maastricht, the Netherlands.
E-mail addresses: a.stoli@maastrichtuniversity.nl (N. Stoli), k.horstman@maastrichtuniversity.nl (K. Horstman), o.zvonareva@maastrichtuniversity.nl (O. Zvonareva).

https://doi.org/10.1016/j.ssmqr.2025.100692
Received 8 May 2025; Received in revised form 15 December 2025; Accepted 17 December 2025

medicine. DIY medicine shares many characteristics with DIY biology (DIYbio). Standing at the intersection of citizen science and hacker culture, DIYbio promotes the democratisation of science through open knowledge-sharing practices that reconfigure the boundaries between "amateurs" and professionals (Meyer, 2013). Wexler (2022) provided an overview of DIY medicine, characterising it as a form of biomedical citizenship in which patients develop therapeutic treatments for their own medical conditions to address a gap in the existing therapies that are available conventionally. An example was the development of an automated insulin delivery system by type 1 diabetes patients and their carers to improve day-to-day living with the disease (Jansky & Langstrup, 2022). Another example is the production of insulin in the United States by the Open Insulin Foundation. Founded in 2015, in response to insulin's exorbitant price, its goal was to produce open-source, freely available insulin. As a non-profit organisation and a community biology lab, Open Insulin presents itself as an example of DIY-biomedicine or DIY-biohacking (OpenInsulin, n.d.). Such endeavours, in which patients collaborate on DIY medical treatments that are either as-of-yet unavailable or available but inaccessible, are supported through the use of the internet, where online health communities can be formed at a rapid pace and medical information is easier than ever to find.

DIY medicine and DIYbio have amassed both positive and negative reactions in recent scholarship. Scholars from various disciplines (Calvert, 2012; Delfanti, 2014; Ferretti & Pereira, 2020; Meyer, 2013) have applauded the innovative, creative and citizen-centric structure of DIYbio communities operating worldwide but have also noted risks and safety concerns that are part and parcel with scientific work that operates outside of any formal regulation frameworks. For instance, Ahteensuu's (2017) chief concern about DIY synthetic biology and genome editing is bioterrorism, in the absence of top-down supervision from a regulatory body. Although such DIY practices constitute a blind spot within the regulatory framework (Gallegos et al., 2018), Burnside et al. (2020) have argued that when financial barriers limit one's access to life-saving medications, DIY medicine and, specifically, DIY pharmaceuticals can be seen as a legitimate access pathway.

Against the background of these debates, we explored a specific case of DIY pharmaceuticals within the broader field of DIY medicine: the production of hormones by a digital transgender community. We were particularly interested in how this community produced knowledge that served as a credible basis for community members to make and consume hormones. Our aim is to show how citizen drug developers construct and perform standards of safety and efficacy outside formal laboratory spaces and in the absence of external supervision. We first sketch the transgender healthcare landscape and describe the problems that people who seek to transition face in accessing hormone replacement therapy. Next, we delineate the theoretical background of our study. After describing the methodology, we present the results of the analysis. In the discussion, we reflect on how credibility in DIY pharmaceuticals is performed and what can be learned from this.

1.1. *Obstacles in accessing hormones*

Hormone replacement therapy (HRT) is an indispensable aspect of transgender healthcare. Alongside surgical procedures, it plays a pivotal role in what is both medically and colloquially called "transitioning", a process by which transgender individuals align their physical appearance and secondary sexual characteristics with their gender identity. Transitioning lessens feelings of body and gender dysphoria and improves the psychological well-being and quality of life of transgender individuals (Restar et al., 2022; van Leerdam et al., 2023). HRT is an on-going regimen and any disruption to it can lead to a reversal of its effects. Thus, it is important to have long-term, uninterrupted access to HRT. However, accessing HRT is not always easy or straightforward.

First, access to HRT is not uniform worldwide, as transgender legal rights differ from country to country. On-going political actions can bar access to HRT, with examples including Afghanistan, where gender reassignment has been banned since 2022 (Akbary, 2022), and Russia, where both the medical and legal transitions of transgender people have been banned since July 2022 (TGEU, 2024). Such legal barriers effectively bar all transgender people from conventionally accessing transgender healthcare.

Scholars from various disciplines (Bauer et al., 2009; Blus-Kadosh & Hartal, 2024; Kcomt et al., 2020; Roberts & Fantz, 2014; Snelgrove et al., 2012; White Hughto et al., 2015; Winter et al., 2009, 2016) have shown that even in countries where transgender healthcare is legal, transgender individuals face many issues when accessing healthcare in hospital settings. Some of the issues that transgender people face include negative responses from medical staff. These responses are well documented in the literature and can range from visible discomfort to refusal of services (i.e. gatekeeping) and overt harassment (Bauer et al., 2009; Snelgrove et al., 2012; White Hughto et al., 2015; Winter et al., 2016). Transgender individuals generally have come to expect harassment, which leads many of them to avoid or delay contacting medical services for necessary care, even for health issues other than transitioning (Blus-Kadosh & Hartal, 2024; Kcomt et al., 2020; Roberts & Fantz, 2014; White Hughto et al., 2015). A general lack of knowledge on transgender healthcare issues on the part of doctors limits, in turn, the resources that they have available to offer appropriate care to their transgender patients. This considerably diminishes the quality of care for transgender patients in hospital settings (Bauer et al., 2009; Blus-Kadosh & Hartal, 2024; Roberts & Fantz, 2014; Snelgrove et al., 2012). In addition, evidence shows that 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) have shown that transgender healthcare is commonly left out of insurance plans, and therefore its costs are usually not covered even for patients with healthcare coverage. Adding to this, transgender people face disproportionate rates of unemployment due to societal discrimination, making many of them unable to afford the high medical costs of such treatments. The current landscape of transgender healthcare, as outlined above, provides a critical context for understanding the rise of DIY hormone production. We note that for the purposes of this study, we do not refer to DIY hormone production as the acquisition of hormones from various sources (online pharmacies, social circle etc) besides one's doctor (Rotondi et al., 2013) but instead, we refer to the hands-on practices of producing pharmaceuticals at home which have not yet been addressed by social science scholars.

2. Theoretical background

To study DIY hormone production, we draw from theoretical discussions in Science and technology studies (STS) about knowledge credibility, about patient participation and about citizen science.

STS scholars have extensively examined how scientific knowledge and credibility are constructed. Instead of taking the norms of "objective scientific knowledge" for granted, they have studied how these norms are constructed in specific socio-historical contexts. In their work *Leviathan and the Air-Pump: Hobbes, Boyle, and the Experimental Life*, Shapin and Schaffer (1985) described how in the 17th century the experimental empirical methods of Boyle gained credibility in the context of intellectual controversy and a politically protected scientific community – the Royal Society of London. This was achieved through the establishment of social spaces and practices such as "virtual witnessing'' and norms such as openness and replicability. In their work, Shapin and Schaffer (1985) posit that when science develops as a practice in which claims about the production of credible knowledge are made, certain rules, regulations, and rituals are developed to allow the checking of knowledge claims. As such, practices that placed emphasis on transparency and control became part and parcel of credible knowledge production in scientific settings and greatly affected the norms of "objective scientific knowledge" from that point onward. However, as

Gieryn (1983) showed, the norms for credible knowledge and the boundaries between science and non-science are simultaneously constructed and contested, and what counts as scientific knowledge is not self-evident.

In Shapin and Schafer's historical account of 17th century England, practices of virtual witnessing were co-produced with early scientific institutions, but in the changing context of public accountability in the 20th century, scientific institutions developed new practices of credibility. For instance, in his historical analysis *Trust in numbers*, Porter (1995) shows how numbers and other quantitative technologies gained credibility in the social sciences, particularly after World War 2. This was achieved due to the quest for impartial advice in democratic policy dynamics and due to numbers' perceived impartiality and objectivity, which in turn imparted credibility to the scientists who yielded them. This shift to quantification produced a cultural and social correlation between statistics and credible knowledge production in science. Mackenzie (2007, 2006) demonstrates how this quantification works out in economics, by using a specific quantification technology as his example, namely the Black-Scholes (or Black-Scholes-Merton) option pricing equation. He shows that the transformation of academic finances, the professionalisation of US business schools and the transition of descriptive economy into theoretical and quantitative models (p832, 852), allowed this fundamental equation of modern financial economics to gain credibility. Callon (2008) posits that economists perform economics: they do not describe pre-existing worlds but in fact actualise them and a host of human actors (academic economists, accountants, marketers and more) and non-human actants (statements, models, analytical tools) engage in the construction of specific quantitative credibility tools.

This shift to quantification technologies as the arbiter of credible knowledge production can also be seen in the gradual standardisation of healthcare and medicine in the 20th century (Fernandez et al., 2015). The widespread adoption of evidence based medicine (EBM) and more specifically, the randomised clinical trial (RCT) method as the golden standard for both clinical practice and policy-making decisions in healthcare testifies to this (Fernandez et al., 2015; Jacups & Bradley, 2023). Several STS scholars have critically analysed the rise of EBM and have shown that knowledge practices that rely on RCTs disregard the complexity of health issues (Jacups & Bradley, 2023). Additionally, EBM privileges certain types of knowledge versus others, thus limiting the impact of 'evidence' derived from patients' knowledge, whose 'embodied' insights and experiences are often deemed irrelevant or untrustworthy (Moes et al., 2020).

STS scholars such as Epstein (1995, 1996), Rabeharisoa and Callon (2002, 2004), and Whelan (2007) have shown how discussions about credible knowledge are connected with the rise of patient participation. Epstein (1995, 1996) showed how patients living with HIV/AIDS in the 1990s contested the norm for "good medical research'' in HIV/AIDS drug testing. That norm entailed that patients could not participate in several trials simultaneously to increase their chances for receiving a working drug and living longer. Their concurrent participation in several trials would interfere with the idea of a "clean body" as a condition for producing "objective knowledge" about safety and efficacy of drugs. In response to this, these patients introduced pragmatic considerations for inclusion and exclusion in these trials and argued for compromises between knowledge production and quality of life of patients. In a similar way, Whelan (2007) analysed how the case of an online endometriosis patient community based in the US and Canada collectively produced knowledge claims about endometriosis by positioning the personal experience of the condition as the arbiter of medical truth. In their recent study of the Israeli transgender community, Blus-Kadosh and Hartal (2024) showcased how members shared life-saving information about pelvic floor physiotherapy to prevent possible post-operative recovery complications; this information was not provided by doctors in formal hospital settings. While the community's role was crucial to the physical wellbeing of transgender patients who had undergone gender affirming surgery, interviewed members of the community felt that their experiential knowledge was discredited systematically by medical professionals. In their study of the AFM, Rabeharisoa and Callon (2002, 2004) explored how patients living with understudied rare diseases, alongside their caretakers, developed their own knowledge claims on the disease as "researchers in the wild", whose knowledge was as important as the knowledge produced by scientists in a laboratory setting. By creating written accounts of their observations and sharing them with medical researchers, they allowed for transparency and control and therefore partook in the norms of good science.

Debates around credible knowledge are not only reflected in studies of patient participation but in citizen science studies as well. The term citizen science refers to a wide range of activities involving citizens (citizen here often meaning non-professional, rather than a member of a specific nation state) in scientific knowledge making. Often viewed as a participatory research model (Strasser et al., 2019), citizen science can include a diverse subset of practices, from citizens collecting observational data in fields such as astronomy and ornithology, to patients cataloguing and sharing symptoms of illness in online forums. Examples like citizens cultivating cannabis for medicinal purposes (Aguilar et al., 2022) and biohackers producing insulin in community laboratories (Strasser et al., 2019) show how citizen science can populate grey legal areas. Scholarship on citizen science has paid attention to the dynamics of collaboration between citizens and professionals. Rowbotham et al. (2019), for example, has divided citizen science into three distinct levels; a. contributory (citizens are only involved in data collection), b. collaborative (citizens are further involved in data analysis and interpretation) and c. co-created (citizens take part in problem definition and research finding translation). While some scholars consider citizen science as an instrument for data collection to analyse problems that are defined by professional scientists (Elliott & Rosenberg, 2019), other scholars such as Raap et al. (2024) highlight the ways in which citizen science can actually democratise science by introducing new issues of public concern. Examples of citizen science that is grassroots and citizen-led, robust in its knowledge making but not necessarily in collaboration with professionals, have not received much scholarly attention yet.

Examples of patients or citizens producing knowledge claims challenge common notions of "good science." We analyse the performing of credibility in the context of patient/citizen involvement in healthcare and pharmaceuticals. We explore how an online community of transgender people aiming to produce hormones for personal use deals with credibility. To be sure, we do not evaluate the safety and efficacy of the produced hormones. By looking at their practices through the lens of constructing credible knowledge claims and by employing the concept of "virtual witnessing", we seek to understand how this community of citizen drug developers constructed and performed standards of safety and efficacy.

3. Methodology

3.1. The community

This paper focuses on an online community of transgender activists involved in DIY pharmaceuticals, connected via a discussion-based forum with worldwide membership. The internet is a critical factor in the formulation of a global community of this kind, since it allows LGBTQA+ individuals from all parts of the world to meet in a safe virtual place where they can anonymously explore issues of common concern regardless of their location (Charmaraman et al., 2022; Hillier & Harrison, 2007). Although other languages were occasionally featured in the forum, most content was published in English. All posts and comments were publicly available and its members used pseudonyms for anonymity. Members also had the option of private messaging. Forum administrators had set rules of conduct to ensure the longevity of the community, including an age of majority limitation for participation.

The forum mostly served as a meeting place for what the community described as scientific work and experimentation. Its purpose was to enable the home production of hormones that were deemed safe and cheap and to facilitate the transitioning journey of members using hormone replacement therapy (HRT). The community encouraged its members to first educate themselves on the topic of hormones by reading published academic papers and books, then perform experiments related to hormone production, and finally share the results with others. Successful experimentation led to guides that were posted in an archive within the forum for other members to repeat the procedures at home or modify as needed. In addition to this main function of producing hormones at home, the community also served as a hub where like-minded individuals could share their concerns and receive personal advice and emotional support.

3.2. Data generation and analysis

We relied on a qualitative study of an online forum to generate our data. First, Author NS joined the public discussion-based forum, with a pseudonymic username, as is commonly done in these communities, and contacted the administrators, as per research protocol. In the private messages sent to the administrators, Author NS identified herself entirely, sharing her real name, the full research plan, as well as links to further information and identification. In the same message, Author NS requested interviews from the administrators of the forum. The administrators did not respond to the author's private message but read the messages, as indicated by the website's messaging feature. Therefore, Author NS was not able to conduct interviews but was able to remain a member of the community. The refusal of interviews is perhaps indicative of a sense of distrust trans communities may experience towards institutions, as a result of the growing hostility towards them in recent years. This hostility is demonstrated in various forms, from journalistic articles to political parties in various parts of the world limiting their overall rights and access to healthcare. To respect their wish for non-engagement, community members have not been contacted again.

Following this, Author NS moved to generating data from all publicly available posts and comments in the forum itself. The forum was founded five years ago and has since steadily gained traction. Author NS selected discussion posts with the highest percentage of engagement level (as measured by "likes") from the forum's foundation for the duration of five months. Incorporation of data stopped when discussion themes began repeating themselves and data saturation was reached. Atlas.Ti software was used to catalogue, thematically analyse, and structure the data.

To analyse the data, Author NS developed a research codebook by discussing the emerging categories and relations with the other authors. This led to removal, repositioning, and addition of codes throughout the data generation and data analysis process. While Author NS thematically analysed the data with the other authors, they ensured alignment of the research question, thematic categories, and units of coded text. Thematic analysis of the generated data provided insights into a rich tapestry of themes, ranging from the barriers community members faced when accessing hormones via formal healthcare routes to the various practices and tools employed to circumvent those formal routes and to otherwise access the care they needed. In this paper, we focus on the question of how community members constructed credible knowledge practices that were considered safe and effective, especially considering that this DIY practice falls firmly outside the regular loci of pharmaceutical production, such as the laboratory and the manufacturing industry.

3.3. Ethical concerns

This research focused on a community that faces varying degrees of disapproval, hostility, and outright legal punishment for their gender identity. Therefore, we ensured anonymity of the community by removing references to information, such as the platform in which they operated, the group names, and all personal details of the community members. Author 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 was FHML-REC/2023/008. We conducted our research in accordance with the relevant guidelines and regulations.

4. Results

We have identified three processes that were central to the construction of credible knowledge that the community of transgender activists relied on to ensure the safety and efficacy of their DIY hormones. These are specific strategies of collecting and organising information, of sharing experiences and providing feedback, and of making precautions when navigating new scientific ground. Taking place in an online space that operates outside traditional regulatory contexts, these strategies allowed for a contemporary version of virtual witnessing. By employing these strategies, the community members invited each other to 'look into' an otherwise private process, with the goal of making sound products and minimising harm.

4.1. Making an archive

To enable hormone production at home, founding community members set up a forum, with an archive placed within. The archive contained different types of instructions on how to produce hormones, which the members colloquially named 'recipes.' They collected information on hormone production and hormone treatment and subsequently organised its storage in the archive in a rather transparent way so that information was easily accessible by the forum members. They distinguished these recipes into three different types; basic, user and experimental. As we have experienced ourselves, the structure of the archive allows its visitors to navigate it with ease.

Before presenting the various ways in which the making of the archive ensured credible knowledge practices, we will contextualise the particular use of the term 'recipe'. The word recipe was used throughout the forum and within the archive in place of other words such as 'instructions' as a metaphorical link between DIY-HRT and cooking. This can be seen in this quote from the archive:

> *Imagine it a little bit like cooking. We will tell you how to make a cherry pie on your own at your home. We will suggest ways to make your pie better, even cheaper than the one you get at the supermarket. We will inform you of the risks that various ingredients have and which ingredients you can remove altogether. We will compare the original recipe you found in your grandmother's cookbook with the most recent research we have from food scientists. Of course, you will have to get the most important part on your own: the cherries. And it is not a cherry pie that you are making :)*

This metaphor was not found solely in this particular forum. Open Source Estrogen (Open Source Estrogen — Mary Maggic Official, n.d.) is an interdisciplinary research programme by Mary Maggic, a nonbinary Chinese-American artist and researcher who combines biohacking and speculative design. Within this programme, a 10-min video titled "Housewives Making Drugs" (Housewives Making Drugs — Mary Maggic Official, n.d.) showcases two trans-femme stars, Maria and Maria, teaching the audience how to make their own hormones in a kitchen while discussing issues of access to hormones and body and gender politics. Although this video is scripted in the form of a fictional cooking show and not an actual demonstration of DIY-HRT, it demonstrates how DIY practices can transform the private home and kitchen into a kind of laboratory. Such textual and visual representations are particularly poignant in spaces where body and gender politics, including the patriarchal imagery of women in the kitchen, are a point of discussion. As hormonal production takes the form of a cherry pie recipe, laboratory work becomes cooking, and science is thus domesticated.

Moving to the making of the archive itself, we identify the use of diverse sources of information as an important first aspect in the way it is set up. In order to facilitate the making of these recipes, the archive included information on hormone replacement therapy (HRT) that came from a broad variety of sources and was regularly updated to provide the most up-to-date content possible. The archive contained links that led to textual sources, such as legal and technical documents (patents), published biomedical articles, pharmaceutical company websites, and other industry and academic information distribution channels. These sources provided information about different facets of HRT, from the production level to the consumption level. On the production side, some sources linked to patents that were then reverse-engineered, providing a step-by-step process of making hormones. On the consumption side, the archive provided links to pharmaceutical websites where drug label information listed the possible side effects of hormone treatments based on different dosages. The archive also linked to non-profit websites with instructions on how to submit substances for drug testing for purity and even bodybuilding forums where members shared decade-long trial-and-error attempts to refine or improve hormone formulas. Furthermore, the archive contained audiovisual sources, such as educational videos hosted on public platforms that demonstrated the proper safe handling of medical equipment and substances. These audiovisual sources served as tools that the forum members could use to apply the knowledge that they had read. The diversity of sources in the archive allowed the community to approach HRT from different angles, to use information and materials from diverse disciplines and sources, and to eventually compare them. Additionally, the audiovisual tools helped members understand the sources and correctly perform experiments in producing hormones in a way that they deemed safe and successful.

Another important aspect of making this archive was the administrators' decision to divide the hormone recipes into three concrete types: basic, user and experimental. Basic recipes served as a baseline, a starting point for any member interested in making their own hormones. They were published on the archive by the administrators and were the result of various sources of knowledge condensed into a single piece of text. The recipe text gave explicit and streamlined instructions on how to make hormones at home. Before the instructions, a paragraph explicitly stated which sources the instructions were based on, from published biomedical literature to mostly (but not always) expired technical patents. Anyone who wished to engage with the primary sources could click on the provided hyperlinks. The recipe then listed the materials, equipment, and specific measurements needed to create a specific amount of hormones for personal use. This information was in the form of a series of sentences, written in biomedical language but stripped of excessive technical details. This step-by-step guide condensed an amalgamation of different sources with data pulled together from academic and industry channels, creating the new text. Here we show a rephrased excerpt of such a basic recipe found in the archive:

> *Generic [hormone] from Zero*
>
> *We have discovered how to make a generic version of the currently marketed* [product], *which has been proven to be safe and effective, in a simple way. Based on patent* [number], *it seems that the original formula for commercial* [redacted] *at regular strength* [percentage] *is pretty straightforward:*
>
> [recipe provides a list of ingredients and their quantities written in biomedical language and with numerical specificity]
>
> *This simplified formula was derived from information found on page [number], line* [number] *of this patent, as is similar to the* [alternative product] [percentage]*, and from line* [number] *of this other patent, which is similar to the* [alternative product] [percentage].

Although the introductory paragraph of the recipe allowed readers to check the original sources for themselves, a basic recipe lacked a description of how exactly the synthesis was performed.

It is interesting to note that most of the primary sources cited at the start of the basic recipe were not specifically about transgender people transitioning via hormone therapy. An example is a cited article that discussed cisgender women suffering from hormonal deficiencies and how hormonal treatments could resolve this issue. In this article, the concentration of estrogen needed to stabilise these women's hormonal deficiencies was considerably lower than what a transgender woman would need for HRT. As such, the basic recipe's ingredients reflected this change from the primary sources, as the numerical data of the article were modified to fit the needs of the transgender users of the basic recipe. The basic recipe informed the reader as to what information from the primary sources could be disregarded, what information was useful to keep in mind, and how this information had to be transformed to fit the needs of the transgender users. However, most of the decisions made to arrive at a specific basic recipe were invisible to the reader and were not explicitly described in a methodology section for the readers to "follow along". As such, should the reader choose to engage with the primary sources via the hyperlinks provided, they would need to determine their own path of modifying the data provided to them. The following excerpt shows how a basic recipe informed the reader of the method of extrapolating data from primary sources:

> *We sourced and extrapolated data from an article that discusses the treatment of cisgender women who suffer from hormonal deficiencies. For us, transgender women, higher doses are needed to increase the concentration and to obtain the same levels. We are using transdermal applications, and we will decide on the total volume* per *dose based on the concentration of* [hormone] *in the solution we have made.*

A final important aspect of making this archive was the technical work put into making this online structure easy to navigate. The archive administrators engaged with a variety of different sources, collecting tidbits of knowledge that were then metaphorically pushed through a sieve, keeping only what was useful for enabling hormone production at home. Methods, ingredients, substances, and risk assessments were considered and rewritten into cohesive texts that operated as an easy-to-follow single source for DIY-HRT. The hyperlinks in the basic recipes ensured the transparency of the archive, while the step-by-step instructions allowed readers to repeat the recipe while choosing the degree of engagement with the primary source material. Basic recipes lacked the traditional methodology section of a published academic review, where each step of the process is meticulously described in the text and instead provided a general method or research question for the reader to work through the primary sources themselves, should they wish to confirm the validity of the end result.

The community involved in setting up the archive did not simply collect sources on HRT to a single location for easy retrieval; instead, they carefully checked the origin of the sources, chose which sources fit the needs of the community best, organised them in a way that served the community's DIY purposes and presented them in a condensed 'no-frills' manner to assist members with various educational backgrounds to navigate through them and begin their own DIY hormone production journey. In the process of making the archive, they transformed biomedical sources into something useful, accessible and credible for their particular purposes. In the words of a community member:

> *I was one of the people responsible for the creation of this forum. While* [administrator username] *was bringing forward links to academic papers and formulas, I was collecting and compiling this information into something that the average reader can actually digest.*

So, the archive was not just a neutral hatch, but a process in which choices were made that contributed to the credibility of the materials that were presented. The archive's structure allowed the community members to perform credibility checks by means of virtual witnessing in an online environment.

4.2. Making user recipes

Unlike the basic recipes that were compiled and posted by the administrators in the archive, the second type of recipe (user recipes) was publicly shared by the forum members in the website's discussion board. By sharing them as discussion posts, other forum members could comment underneath, making this type of recipe open to direct interactions. User recipes were not stripped-down authorless guides but personal posts, where members described in detail how they made their "own recipe" for hormone production at home. As such, user recipes diverged from basic recipes stylistically, featuring more diverse and personalised content that differed from recipe to recipe. Some who published user recipes explicitly referenced a basic recipe while describing their own user recipe, crediting it as a knowledge basis or as an inspiration. Others did not reference a basic recipe but instead referenced other members' insights and observations, as shared in various discussions in the forum. User recipes enabled other community members to check what was being done in an individual "kitchen" and to ensure that safety and efficacy were kept in mind in that process. Using the comment section, other members confirmed the safety and efficacy of particular user recipes by sharing their own success in repeating the recipe at home. Once deemed safe and effective by enough commenters, the administrators added those user recipes to the archive, under the respective category.

There are various reasons why a member may have chosen to make their own recipe, instead of strictly following one of the basic recipes. Some experienced financial difficulties and searched for cheaper alternatives to replace the original recipe's more costly ingredients or equipment, where such change was possible. Others kept equipment and ingredients unchanged but scaled the quantities up or down to accommodate personal needs. One example was decreasing the output quantity due to a lack of space to safely store the end product, since hormones need to be stored in cold temperatures. Different needs led to different recipes, and as the members modified aspects of the DIY-HRT process, they publicised the steps they followed in the forum for peer scrutiny. This way, community members allowed for critical checks and feedback of other community members from all over the world, contributing to the credibility cycle in the community.

User recipes occupied a specific space within the forum, making them subject to checks, comments, and feedback in the form of comments. Unlike basic recipes, which featured text that was embedded in the archive itself, user recipes could be found in the archive as hyperlinks, which led back to an original post published in the forum's discussion board. This was an important distinction because it allowed members to see all comments underneath the user recipes. In the post itself, users shared the steps they took to produce the hormones, the motivations behind any changes they had introduced, and, most importantly, the sensory experience of producing and consuming the end-product. They noted what they deemed worthy of sharing in regard to the taste, smell, texture, and appearance of the product, bringing the other members as close to (virtually) witnessing their work as possible. Although most user recipes were posted in the form of only text, some forum members also provided audiovisual guides with photos and videos of the process. In the comment section, other members shared their own insights, enquired into parts of the process, provided advice that came from personal experience, and asked clarifying questions. The original poster often responded to these comments, sharing more of their experience or using these new insights to improve the recipe. In the following excerpt, the original poster asked other members for help regarding a burning sensation when applying the end product transdermally. The comments addressed this enquiry and led to improvements in the user recipe:

> [Commenter] *I have attempted this using* [x, y ingredients] *and they worked very well! So perhaps you should try to make your recipe again, only this time first add the* [ingredient x] *instead of the* [ingredient y] [commenter proceeds to describe their own process of making this product].
>
> *And don't forget! Always rub the gel first before adding* [z ingredient] *to check if it burns you because your skin is very sensitive. Let me know how it worked out, good luck!*
>
> [Original Poster] *Oh wow, thanks a lot! Your comment helped a ton. So, if I do this* [proceeds to write a modified version of the recipe based on the feedback]*, the consistency of the whole mix will be more like a gel and using less* [ingredient] *hopefully means there will be a milder burning sensation as well. Thank you again!*

To safeguard the quality of the recipes and because of the global character of the community, the archive predominantly used the English language for communication. Even in cases where the original poster prefaced their text by mentioning their non-English-speaking country of origin, the recipe would still follow in English. Similarly, despite differences in units of measurements from country to country, members used the International System of Units (SI) for their recipes, for example, describing substance quantities using grams and millilitres and temperature using the Celsius scale. Using common language(s) served as an equivalent of standardising scientific guidelines or instructions, a very common practice in scientific communities, and it made it easier for the members of this specific community to "see" and follow each other's practices. User recipes were written and shared in such a way as to encourage fellow community members to 'look into' an otherwise private process. While each community member individually produced hormones at home, the user recipes allowed for credibility checks by means of 'virtual witnessing'.

4.3. Making precautions

While this community wanted to help its members transition by overcoming obstacles in healthcare systems and supporting DIY-HRT, they were acutely aware of the complexity of the processes involved in making your own hormones at home. This made ensuring the safety and efficacy of the end product an issue of paramount importance. This is particularly evident in the last type of recipe found in the forum's archive: the experimental recipe. The experimental recipes found in the archive came with many safeguards. In the face of uncertainty, much attention was paid to teaching fellow members how to cautiously navigate the new scientific ground and to the practicalities of making hormones.

The basic, user and experimental recipes in the archive were categorised in various ways, including the route of administration (transdermal or sublingual), the concentration levels in the solution, and more. Some of these categories were considered well researched by the global biomedical community and therefore included minimal warnings. Basic recipes, for example, included creating gels for transdermal use, as the community members considered superficial application on the skin safe overall. In contrast, other routes of administration, such as injections, were deemed riskier and were generally avoided. Similarly, user recipes fell well within the drawn borders of "safe science," citing appropriate references and diverging from the basic recipes in ways that did not introduce much uncertainty. In comparison, experimental recipes were undertested, both by the larger biomedical community and the forum members themselves. Sometimes, these recipes contained insights from non-academic and non-industry sources, such as bodybuilding forums. Other times, they drew upon biomedical sources that were purely theoretical, as no empirical work had been done to test their hypotheses. Either way, experimental recipes were considered to present a higher level of risk than other parts of the archive, and those who engaged with them were consistently instructed to take appropriate precautions. The following excerpt from the archive illustrates how the different routes of administration were described in terms of calculating risk:

> *We believe applying a gel to the skin surface is inherently safer than any type of injection. When you make your own hormones, safety is paramount. It is hard to stay safe outside of a professional laboratory, so homebrewing hormones should be designed in a way that is fail safe. If you do something wrong, the consequences of putting it on your skin will be much less than injecting it inside your body.*

In consideration of these risks, the online community embedded diverse precautions in the DIY process.

The first way to make precautions was to put warning signs in certain subsections of the archive. These included titling the subsections with the word "experimental" at the very beginning of each recipe name and using cautionary language and punctuation, such as exclamation points, within the text. In addition to the use of certain wording, typographic tools were used to imbue the text with emotion and emphasis. Such tools included the use of **bold** or *italics,* which aided in stressing the warnings and differentiating them within a block of text. These tools did not forbid people from engaging with the content but served as signposts, encouraging the reader to pay special attention. Two illustrative excerpts follow; the former shows how wording served as a sign post, while the latter shows the use of typology to serve the same purpose:

> *Some of these ingredients that achieve* [effect] *can cause significant health problems and perhaps even health complications. If you want to use this formula, you need to fully understand what risks are involved! Using these substances without a full understanding can be very hazardous!*
>
> –
>
> *Please don't forget to place name tags on the medication you made, so you know which is which! Others might mistake them for a fun cocktail and drink it by accident! Drinking it without realising or drinking too much can lead to health complications!* ***Do NOT use*** **[ingredient]** ***or anything else that could be toxic!***

In addition to these warning posts, those who posted in the discussion board were sometimes alerted by other members of entering dangerous territory via the comment section. Despite the archive's warning posts, members may have unknowingly or accidentally "trespassed" into uncharted territory. One common mistake was users posting recipes under "user recipes" that, in fact, fell under the category of experimental recipes. When this took place, other members witnessed the untested and potentially risky elements and sounded a metaphorical alarm. In the comment section, they informed the original poster of the potential risks and blindspots, encouraging them to be more alert. In the following excerpt of a user recipe, some of the observations indicate that the recipe had introduced untested elements, such as tasting the substance instead of using it transdermally:

> *I was surprised to note that the powder doesn't taste sweet. I found it incredibly bland-tasting. I was expecting it to taste really sweet, much like* [other product], *but not at all.*
>
> *I tested this using plain alcohol. I don't believe I can do it sublingually because the moment it hits my mucosa, I start to salivate. My gums can probably handle it better, so maybe I'll try that tomorrow?"*

In response to these observations, a community member voiced concern, noting the potential risks of pursuing this route of experimentation with the use of cautionary language and a plethora of citations from secondary biomedical literature to support their claims. It reads as follows:

> *I think what you're doing right now is way beyond your abilities. Did you actually mix the powdered* [ingredient] *into alcohol and then drink it like a cocktail? If your goal was to make a spray, then that goes on the skin. If your goal was an injection, that is injected, I don't think there is a method for making something you consume.*
>
> *This kind of thing isn't meant to be improvised like this, without any preparation* […]
>
> *Honestly, I am not certain what happens if you decide to consume this orally. I would assume that the dose would be hard to measure since you only need a very small amount to get to the right levels. If you are actually making this into a drink, something is definitely wrong.*
>
> *If I haven't made it obvious how likely it is that you will overdose because of this,* [commenter offers numerical evidence of overconsumption due to change in administration method] *if you're consuming this amount on a daily basis, you must have a death wish.*

Members let each other know they should "tread carefully" by highlighting the inherent risks of breaking new scientific ground.

A third way to make precautions was to underline the importance of preparing adequately. Both in the archive and in the comment sections of discussion posts, community members placed value in arming oneself with the knowledge needed to undertake this challenge. In the following excerpt, we see another comment from the same discussion post of a user's recipe in which a different member encouraged experimentation while still placing guardrails in the form of secondary literature citations:

> *We don't have much data on this method so you didn't do anything wrong* […] *it's just that you're attempting to create something very different than the usual and it is not documented yet.* […] *you've got a lot of work to do, but it looks like a very original and very cool project and I don't see any issue in what you're planning that is impossible to fix* […] *It can work, but it will need experimentation on your part.*
>
> *What I would suggest:*
>
> - *Try changing the concentration of* [substance].
>
> - *At this point* [reference to a stage in the recipe], *change the temperature of* [tincture] *from cold to warm.*
>
> - *After* [suggested amount of time], *do a blood test at a laboratory to check your levels* […]

While this DIY community enabled experimenting with recipes, it underlined in many ways that those who wished to do so needed to possess the knowledge, tools, time, and determination to succeed. Once a specific post raised alarm, community members guided its author to all available resources and offered themselves as "sounding boards", as co-experimenters whose knowledge and insight could help fill in the gaps. They suggested not only exercising caution and responsibility but also patience, as they prompted new experimenters to not rush through the process and instead take their time to familiarise themselves with the various elements of DIY-HRT. They also encouraged those with professional biomedical expertise to share their insights and perhaps to test these ideas in a proper laboratory should they have access to one.

It is important to note that trustworthiness of feedback and comments was not based on the professional biomedical training of a member. In conversations in the comment sections of various discussion posts in the community, members gave advice without necessarily prefacing how they acquired their knowledge. While professional education was not a self-evident authority basis, some members who explicitly called themselves professionally trained scientists or cited the many years of experience with hormone therapy, received positive feedback. People who had gotten that information via other routes were nevertheless considered trustworthy. In the following example, a member referred to a doctor's advice given to them and another member responded to that:

> *1. (in reference to another member talking about a doctor's advice for them) Oh that's quite interesting.*

> *I am not a doctor and I really do not want to question the validity of what they told you but studies and research on (subject matter) actually imply something very different than what your doctor told you.*
>
> *(member continues their comment, describing their alternative viewpoint and offering appropriate citations to articles to back it up)*
>
> -
>
> *2. (different member responding to another member's comment on a potential HRT recipe)*
>
> *That is an excellent response! (I'm a professionally trained pharmacist)*
>
> *(response from an administrator)*
>
> *Could you perhaps look into some of our proposed recipes? Based on what I have read, they seem good but I'm not trained as a pharmacist and you are.*
>
> *3. (member giving advice to another member in a different comment section)*
>
> *Hello! I am going to tell you what my opinion on this is because I've been on the same (HRT) therapy as you for two years (what are the chances, huh?).*
>
> *(member proceeds to describe a specific dosage regime, including information such as blood test baselines and what they might mean)*

Conversations amidst community members indicated that being thorough, descriptive, well-informed, as well as having experience on the matter were traits that the community members associated with trust and authority on equal grounds to having professional biomedical training. Establishing safeguards in the archive and warning other community members of potential pitfalls in the comment sections of forum discussions, encouraged openness, transparency and critique. By means of virtual witnessing, the community worked towards minimising harm that came part and parcel with more experimental approaches of hormone production.

5. Discussion

When it comes to patient participation, DIY medicine is perhaps one of the most radical practices, since it entails people producing pharmaceutical products outside the biomedical professional context. While some see DIY practices in the field of biomedicine as an important contribution to making science (and pharmaceuticals) more accessible (Meyer, 2013; "Opening the Door to Backroom Biologics," 2019), others are concerned because they are developed outside established regulatory contexts, challenging scientific norms and procedures for assessing safety and efficacy (Delfanti, 2014; Meyer, 2013; Rasmussen et al., 2020). We studied a particular case of DIY biomedicine in which citizens turned drug developers addressed obstacles in accessing hormone therapy in transgender health care by setting up an online forum to help each other produce their own hormones at home. In our view, this example of DIY hormones can be seen as democratising healthcare, by opening it up to broader ranges of actors and types of knowledge. Concurrently, these DIY hormone practices operate on a regulatory blindspot and are, therefore, subject to safety uncertainties. Without an external regulatory safety net and with an aim to prevent members from harming themselves and others, this community's members put a great deal of work into developing DIY hormone production as a credible practice that continuously takes safety and efficacy into account. Based on a qualitative study of this forum we identified three different processes that were central to the construction of credible knowledge to facilitate the safety and efficacy of DIY hormones.

The analysis first showed that community members established a transparent, easy-to-use archive that contained various sources of information on hormone production and hormone treatment, including audiovisual tools meant to facilitate the understanding and application of these sources. These sources were carefully selected, organised and presented for ease of use to all members regardless of their knowledge baseline. Second, community members encouraged each other to publicly share their process of making user recipes in forum discussions using standardised language. These recipes, shared in textual and/or audiovisual format, were then commented upon by other members who critiqued, supported, or confirmed their safety and efficacy. Third, community members established safeguards through the placement of "signposts" in the archive, including the use of cautionary language and typographic tools. They also did so through the comment section, where members alerted others of entering dangerous territory and encouraged them to equip themselves with more knowledge by providing both emotional and intellectual support as well as additional literature. In terms of transparency and openness to critique, this DIY community resembled a classic scientific community.

Shapin and Schaffer (1985) analysed the development of practices of virtual witnessing to show the construction of credibility in an increasingly international scientific community in the 17th century. The purpose of virtual witnessing at the time was to allow colleagues not physically present at an experiment to follow a procedure and trust the outcome. We suggest that virtual witnessing was a key process in this global DIY community as well. This community performed credibility checks by creating a space that allowed for transparency and for other people to "look into" an otherwise private process. Instead of the physical space of the 17th-century Royal Society of London, in our case, the internet offered a space that allowed for witnessing. Since this forum did not operate in a traditional regulatory context, where an external agency could supervise and intervene when needed, the members invited each other to virtual witnessing in order to make sound products and minimise harm. Without the institutional obligation to ensure standards of safety and efficacy, this community had developed a DIY methodology to collect, produce, and synthesise knowledge driven by the desire to help other transgender people obtain the healthcare they needed. For many of the community's members, these guides to DIY-HRT and the support of peers were the only ways of accessing HRT. As such, practices of virtual witnessing constructed this DIY community not only as credible producers of knowledge and pharmaceuticals, but also as a caring community.

By choosing the theoretical angle of virtual witnessing, we present the community of DIY hormone producers as contemporary successors to the work of early scientists documented by Shapin and Schaffer (1985), but with a key difference. While virtual witnessing in the 17th century was an ingredient of growing institutional collaborations, the online community in our study strove to be self-contained and, unlike the Open Insulin Foundation, did not collaborate with any formal regulatory bodies. In the introduction, we sketched the scholarship on patient participation and on citizen science as relevant backgrounds for this study. Our analysis indicates that the online community stands out from many practices of patient participation and citizen science because its members do not collaborate with any experts affiliated with established institutions. Instead, they assess the quality of knowledge amidst themselves.

Many scholars have argued that patient participation is valuable because patients possess unique experiences. Rabeharisoa and Callon's (2002, 2004) work on the AFM showed a collaboration between patients and medical professionals in which the patients provided valuable content while the norms of credibility of their contribution were set by the scientific institutions with which they engaged. Epstein (1995, 1996) showed that HIV activists also contested institutional scientific trial procedures and succeeded in renegotiating the rules of trial inclusion. They claimed the democratic right to participate in shaping drug experiments and medical treatments. In both examples, patient communities and their carers established strong relations with credentialed experts, who in turn validated the credibility of their contributions.

Our study suggests that this DIY hormone production community performs credibility by developing processes that democratise science in a new way. Its members take care to validate what they are doing, reflect on their experiences, document their "experiments in the kitchen", and signalling precautions, so that others can learn from them. By building in reflection and critical feedback within the community, this DIY community also develops itself a caring community, facilitating transition, but in a safe way and with a focus on personalising the treatment as much as possible. The community performs procedures of transparency and critique that are associated with academia, but in some respects, it can be seen as democratizing these procedures as well, as all community members, whatever their educational background, work together to produce credibility by voicing their insights, providing feedback and sharing their experiences. This case study shows the co-production of the internet as a space for virtual witnessing, and, the democratization as well as the scientification of DIY practices of hormone production at home.

Our study also showed how in this community scientific evidence from diverse disciplines was tailored to the making of hormones for a specific person with specific characteristics and wishes. Standardised, quantified, evidence-based procedures for validating institutional knowledge are mostly based on an average patient and therefore do not necessarily ensure safety and efficacy for all patients; paradoxically, standardisation meant to increase safety and ensure efficacy may in some cases do the opposite. Critical studies of EBM and particularly the randomised clinical trial (RCT) method as the gold standard of producing credible knowledge (Fernandez et al., 2015; Jacups & Bradley, 2023) have made clear that diversity of patients, patient bodies and specific comorbidities are not represented in the focus on the 'mean', often male body. In comparison, the community we study emphasised the personalisation of health care by performing credibility in a caring way. The goal of credibility and producing credible knowledge is continuously connected to people's actual needs and circumstances. In that sense, the DIY community engaged more radically than formal scientific institutions with both '"good knowledge" (as it took a larger circle of people as serious co-producers and critical voices) and with "good care'' (as it enabled serving a large variety of individuals with diverse backgrounds in a rather personalised way). With this in mind, our case study may have some bearings for the discussions in the field ethics of care. While in that field many scholars point to the relational character of care, such as Joan Tronto in her work *Moral Boundaries: A Political Argument for an Ethic of Care* (1993), in our paper we show that it is the careful, meticulous and highly personalised process of collecting, presenting and providing biomedical and pharmaceutical information that might be viewed through a caring lens. In fact, we suggest that it would be interesting to look into other online patient communities to see if such practices of performing credibility and, perhaps, care are present. One such case could be the patients suffering from amyotrophic lateral sclerosis (ALS), first explored by Wicks et al. (2011) in their paper on clinical discovery and self-reported patient data on the website **patientslikeme**. In their paper, they looked into a subgroup of patients that conducted their own study on the effects of lithium carbonate after the publication of a small study in Italy that promised the compound would slow the disease's progression. This patient-led clinical study concluded negatively and led to various clinical trials in the USA and Europe to halt early while many clinicians reported the patient-led study's findings to dissuade patients from self-experimenting with lithium carbonate. Future research could study such communities to ascertain whether or not online virtual witnessing is similarly used to perform credibility and care outside of pharmaceutical research and development.

To conclude, this case study adds to the STS literature on the construction of credibility and virtual witnessing procedures by showing how a particular DIY community performs virtual witnessing in the absence of external regulation and outside of formal laboratory spaces. It also adds to the STS literature on patient participation by introducing a DIY community that did not simply contribute to scientific knowledge by means of unique content but by setting up its own procedures and norms for 'good knowledge.' Furthermore, it expands our understanding of what citizen science can look like when citizens are involved in all steps of the research process but do not collaborate with professionals. As this community set up its own processes to reflect on its experiences and validate its procedures, members developed a practice of scientific care that connects biomedical knowledge to personal needs. This emphasis on personalisation and a partisan 'relationship' to the medical knowledge being produced adds to recent critiques on the credibility of EBM and its inherent exclusion of certain patients (Jacups & Bradley, 2023). This raises the question whether formal institutions can learn something from how this community combines credibility and care. Perhaps, this case study can provide an inspiration for contemporary healthcare institutions to be more democratic and caring in the production of scientific knowledge, while also highlighting how DIY pharmaceuticals can be an unconventional but potentially important pathway for citizen participation in knowledge production.

CRediT authorship contribution statement

Natasa Stoli: Writing – review & editing, Writing – original draft, Investigation, Conceptualization. **Klasien Horstman:** Writing – review & editing, Supervision, Conceptualization. **Olga Zvonareva:** Writing – review & editing, Supervision, Investigation, Conceptualization.

Ethical approval

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 was FHML-REC/2023/008. We conducted our research in accordance with the relevant guidelines and regulations.

Funding statement

This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement no. 948073). This article reflects only the authors' views and the ERC is not responsible for any use that may be made of the information it contains.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to acknowledge all those involved in the WTMC spring workshop (2023) where Natasa Stoli presented her initial findings and whose feedback was of great help in the analysis of this case study.

Data availability

Due to ethical concerns regarding the anonymity of this community, no data will be shared.

References

Aguilar, Ó., Díaz, M. C., & Romero, L. (2022). Citizen science towards the regulation of medical cannabis in Argentina. *Tapuya: Latin American Science, Technology and Society, 5*(1). https://doi.org/10.1080/25729861.2022.2100037

Ahteensuu, M. (2017). Synthetic biology, genome editing, and the risk of bioterrorism. *Science and Engineering Ethics, 23*(6), 1541–1561. https://doi.org/10.1007/s11948-016-9868-9

Akbary, A. (2022). *The predicament of Afghanistan's transgender people*. Afghan LGBT. https://afghanlgbt.com/en/content/tP6w/.

Arksey, H. (1994). Expert and lay participation in the construction of medical knowledge. *Sociology of Health & Illness, 16*, 448–468. https://doi.org/10.1111/1467-9566.ep11347516

Bauer, G. R., Hammond, R., Travers, R., Kaay, M., Hohenadel, K. M., & Boyce, M. (2009). “I don’t think this is theoretical; this is our lives”: How erasure impacts health care for transgender people. *Journal of the Association of Nurses in AIDS Care, 20*(5), 348–361. https://doi.org/10.1016/j.jana.2009.07.004

Blus-Kadosh, I., & Hartal, G. (2024). "We have knowledge that is unique": Patient activism and the promotion of trans-inclusive primary care. *Social Science & Medicine, 344*, Article 116654. https://doi.org/10.1016/j.socscimed.2024.116654

Boardman, F. K. (2017). Experience as knowledge: Disability, distillation and (reprogenetic) decision-making. *Social Science & Medicine, 191*, 186–193. https://doi.org/10.1016/j.socscimed.2017.09.013

Burnside, M., Crocket, H., Mayo, M., Pickering, J., Tappe, A., & de Bock, M. (2020). Do-it-yourself automated insulin delivery: A leading example of the democratization of medicine. *Journal of Diabetes Science and Technology, 14*(5), 878–882. https://doi.org/10.1177/1932296819890623

Calvert, J. (2012). Ownership and sharing in synthetic biology: A “diverse ecology” of the open and the proprietary? *BioSocieties, 7*(2), 169–187. https://doi.org/10.1057/biosoc.2012.3

Caron-Flinterman, J. F., Broerse, J. E., & Bunders, J. F. (2005). The experiential knowledge of patients: A new resource for biomedical research? *Social Science & Medicine, 60*(11), 2575–2584. https://doi.org/10.1016/j.socscimed.2004.11.023

Caron-Flinterman, J. F., Broerse, J. E. W., & Bunders, J. F. G. (2007). Patient partnership in decision-making on biomedical research: Changing the network. *Science, Technology & Human Values, 32*(3), 339–368. https://doi.org/10.1177/0162243906298354

Charmaraman, L., Hernandez, J. M., & Hodes, R. (2022). Marginalized and understudied populations using digital media. In J. Nesi, E. H. Telzer, & M. J. Prinstein (Eds.), *Handbook of adolescent digital media use and mental health* (pp. 188–214). Cambridge: Cambridge University Press.

Delfanti, A. (2014). Is do-it-yourself biology being co-opted by institutions? In A. Bureaud, R. F. Malina, & L. Whiteley (Eds.), *Meta-life, biotechnologies, synthetic biology, Alife and the arts*. MIT Press. http://escholarship.org/uc/item/4nz3p0hf.

Elliott, K. C., & Rosenberg, J. (2019). Philosophical foundations for citizen science. *Citizen Science: Theory and Practice, 4*(1). https://doi.org/10.5334/cstp.155

Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology & Human Values, 20*(4), 408–437. https://doi.org/10.1177/016224399502000402

Epstein, S. (1996). *Impure science. AIDS, activism, and the politics of knowledge*. University of California Press.

Fernandez, A., Sturmberg, J., Lukersmith, S., Madden, R., Torkfar, G., Colagiuri, R., & Salvador-Carulla, L. (2015). Evidence-based medicine: Is it a bridge too far? *Health Research Policy and Systems, 13*, 66. https://doi.org/10.1186/s12961-015-0057-0

Ferretti, F., & Pereira, G. (2020). A new ethos for science? Exploring emerging DIY science “qualities.”. *Futures, 125*, Article 102653. https://doi.org/10.1016/j.futures.2020.102653

Gallegos, J. E., Boyer, C., Pauwels, E., Kaplan, W. A., & Peccoud, J. (2018). The open insulin project: A case study for “biohacked” medicines. *Trends in Biotechnology, 36*(12), 1211–1218. https://doi.org/10.1016/j.tibtech.2018.07.009

Gieryn, T. F. (1983). Boundary-work and the demarcation of science from non-science: Strains and interests in professional ideologies of scientists. *American Sociological Review, 48*(6), 781–795. https://doi.org/10.2307/2095325

Hillier, L., & Harrison, L. (2007). Building realities less limited than their own: Young people practising same-sex attraction on the internet. *Sexualities, 10*(1), 82–100. https://doi.org/10.1177/1363460707072956

Housewives making drugs — Mary Maggic official. (n.d.). https://maggic.ooo/Housewives-Making-Drugs.

Jacups, S. P., & Bradley, C. (2023). Is the evidence-based medicine movement counter-productive: Are randomised controlled trials the best approach to establish evidence in complex healthcare situations? *Public health research & practice, 33*(1), Article 3312303. https://doi.org/10.17061/phrp3312303

Jansky, B., & Langstrup, H. (2022). Device activism and material participation in healthcare: Retracing forms of engagement in the #weAreNotWaiting movement for open-source closed-loop systems in type 1 diabetes self-care. *BioSocieties, 1–25*. https://doi.org/10.1057/s41292-022-00278-4. Advance online publication.

Kcomt, L., Gorey, K. M., Barrett, B. J., & McCabe, S. E. (2020). Healthcare avoidance due to anticipated discrimination among transgender people: A call to create trans-affirmative environments. *SSM Population Health, 11*. https://doi.org/10.1016/j.ssmph.2020.100608. Article 100608.

Mackenzie, D. (2006). Is economics performative? Option theory and the construction of derivatives markets. *Journal of the History of Economic Thought, 28*(1), 29–55. https://doi.org/10.1080/10427710500509722

Mackenzie, D. A., Muniesa, F., & Siu, L. (2007). *Do economists make markets? : On the performativity of economics*. Princeton University Press.

Meyer, M. (2013). Domesticating and democratizing science: A geography of do-it-yourself biology. *Journal of Material Culture, 18*(2), 117–134. https://doi.org/10.1177/1359183513483912

Moes, F., Houwaart, E., Delnoij, D., & Horstman, K. (2020). Questions regarding ’epistemic injustice’ in knowledge-intensive policymaking: Two examples from Dutch health insurance policy. *Social Science & Medicine, 245*, Article 112674. https://doi.org/10.1016/j.socscimed.2019.112674

Open Insulin. (n.d.). https://openinsulin.org/.

Open source estrogen. Mary maggic official. (n.d.). https://maggic.ooo/Open-Source-Estrogen-1.

Opening the door to backroom biologics. *Nature Biotechnology, 37*(10), (2019), 1097. https://doi.org/10.1038/s41587-019-0294-9

Pols, J. (2014). Knowing patients: Turning patient knowledge into science. *Science, Technology & Human Values, 39*(1), 73–97. https://doi.org/10.1177/0162243913504306

Porter, T. M. (1995). *Trust in numbers: The pursuit of objectivity in science and public life*. Princeton University Press. http://www.jstor.org/stable/j.ctt7sp8x.

Raap, S. K., & Horstman, K. (2024). Representing neighborhood health: Exploring citizen science as a democratic force. *Citizen Science: Theory and Practice, 9*(1), 1–12. https://doi.org/10.5334/cstp.722, 12.

Rabeharisoa, V., & Callon, M. (2002). The involvement of patients’ associations in research. *International Social Science Journal*, 57–65. https://doi.org/10.1111/1468-2451.00359

Rabeharisoa, V., & Callon, M. (2004). Patients and scientists in French muscular dystrophy research. In S. Jasanoff (Ed.), *States of knowledge: The co-production of science and social order* (pp. 142–160). Routledge.

Rasmussen, L. M., Guerrini, C. J., Kuiken, T., Nebeker, C., Pearlman, A., Ware, S. B., Wexler, A., & Zettler, P. J. (2020). Realizing present and future promise of DIY biology and medicine through a trust architecture. *The Hastings Center report, 50*(6), 10–14. https://doi.org/10.1002/hast.1194

Restar, A., Dusic, E. J., Garrison-Desany, H., Lett, E., Everhart, A., Baker, K. E., Scheim, A. I., Beckham, S. W., Reisner, S., Rose, A. J., Mimiaga, M. J., Radix, A., Operario, D., & Hughto, J. M. W. (2022). Gender affirming hormone therapy dosing behaviors among transgender and nonbinary adults. *Humanities and Social Sciences Communications, 9*, Article 304. https://doi.org/10.1057/s41599-022-01291-5

Roberts, T. K., & Fantz, C. R. (2014). Barriers to quality health care for the transgender population. *Clinical Biochemistry, 47*(10–11), 983–987. https://doi.org/10.1016/j.clinbiochem.2014.02.009

Rotondi, N. K., Bauer, G. R., Scanlon, K., Kaay, M., Travers, R., & Travers, A. (2013). Nonprescribed hormone use and self-performed surgeries: “do-it-yourself” transitions in transgender communities in Ontario, Canada. *American journal of public health, 103*(10), 1830–1836. https://doi.org/10.2105/AJPH.2013.301348

Rowbotham, S., McKinnon, M., Leach, J., Lamberts, R., & Hawe, P. (2019). Does citizen science have the capacity to transform population health science? *Critical Public Health, 29*(1), 118–128. https://doi.org/10.1080/09581596.2017.1395393

Shapin, S., & Schaffer, S. (1985). *Leviathan and the air-pump: Hobbes, boyle, and the experimental life*. Princeton University Press.

Snelgrove, J. W., Jasudavisius, A. M., Rowe, B. W., Head, E. M., & Bauer, G. R. (2012). “Completely out-at-sea” with “two-gender medicine”: A qualitative analysis of physician-side barriers to providing healthcare for transgender patients. *BMC Health Services Research, 12*(1). https://doi.org/10.1186/1472-6963-12-110.

Strasser, B. J., Baudry, J., Mahr, D., Sanchez, G., & Tancoigne, E. (2019). “citizen science”? Rethinking science and public participation. *Science and Technology Studies, 32*(2), 52–76. https://doi.org/10.23987/sts.60425

TGEU. (2024). TGEU deeply concerned by Russian ban of medical and legal transition. *TGEU - Transgender Europe*. https://tgeu.org/tgeu-deeply-concerned-by-russian-ban-of-medical-and-legal-transition/.

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethics of care*. Routledge.

van Leerdam, T. R., Zajac, J. D., & Cheung, A. S. (2023). The effect of gender-affirming hormones on gender dysphoria, quality of life, and psychological functioning in transgender individuals: A systematic review. *Transgender Health, 8*(1), 6–21. https://doi.org/10.1089/trgh.2020.0094

Wexler, A. (2022). Mapping the landscape of do-it-yourself medicine. *Citizen Science: Theory and Practice, 7*(1), Article 38. https://doi.org/10.5334/cstp.553

Whelan, E. (2007). “No one agrees except for those of us who have it”: Endometriosis patients as an epistemological community. *Sociology of Health & Illness, 29*(7), 957–982. https://doi.org/10.1111/j.1467-9566.2007.01024.x

White Hughto, J. M., Reisner, S. L., & Pachankis, J. E. (2015). Transgender stigma and health: A critical review of stigma determinants, mechanisms, and interventions. *Social Science & Medicine, 147*, 222–231. https://doi.org/10.1016/j.socscimed.2015.11.010

Wicks, P., Vaughan, T. E., Massagli, M. P., & Heywood, J. (2011). Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. *Nature Biotechnology, 29*(5), 411–414. https://doi.org/10.1038/nbt.1837

Winter, S., Chalungsooth, P., Teh, Y. K., Rojanalert, N., Maneerat, K., Wong, Y. W., Beaumont, A., Ho, L. M. W., Gomez, F. C., & Macapagal, R. A. (2009). Transpeople, transprejudice and pathologization: A seven-country factor analytic study. *International Journal of Sexual Health, 21*(2), 96–118. https://doi.org/10.1080/19317610902922537

Winter, S., Diamond, M., Green, J., Karasic, D., Reed, T., Whittle, S., & Wylie, K. (2016). Transgender people: Health at the margins of society. *The Lancet, 388*(10042), 390–400. https://doi.org/10.1016/s0140-6736(16)00683-8