

CHAPTER SEVEN

CISGENDERISM IN MEDICAL SETTINGS: CHALLENGING STRUCTURAL VIOLENCE THROUGH COLLABORATIVE PARTNERSHIPS

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Introduction

This chapter focuses on *cisgenderism*. While some readers may be more familiar with the term “cisgender” as a classification for people who are “not transgender”, some recent research has used the term *cisgenderism* (instead of “transphobia”) to describe discriminatory approaches towards people’s self-designated genders and body diversity (e.g., Ansara & Hegarty, 2011; see also Serano, 2007); *cisgenderism* is increasingly used in activist circles by people seeking language that goes beyond notions of “phobia” to address systemic problems. *Cisgenderism* includes various forms of ideology about people with self-designated genders and/or bodies that are not strictly male or female. I use the term *ideology* here to describe systems of meaning constructed by and reflected in everyday language, gestures, other acts, and images in response to dilemmas of daily life. One form of *cisgenderist* ideology is the assumption that all people with self-designated genders constitute a universally and essentially distinct type of being, as when all people with self-designated gender are categorised as ‘transpeople’ and universally assumed to share a single “community” focused around this category, regardless of their cultural or personal context or self-identification. Another form of *cisgenderist* ideology is the characterisation of body diversity that is not strictly male or female as “disordered”, inferior, or undesirable. Numerous texts focus on theories of “identity”, while ignoring contrasts between *cisgenderist* ideology and our own understandings of our lives. As Viviane Namaste (2000) observed:

our lives and bodies are made up of more than gender and identity, more than a theory that justifies our very existence, more than mere performance, more than the interesting remark that we expose how gender works. Our lives and our bodies are much more complicated, and much less glamorous...They are forged in details of everyday life, marked by matters not discussed by academics or clinical researchers. Our lives and our bodies are constituted in the mundane and uneventful (p. 1).

Cisgenderism in medical settings impedes these otherwise uneventful tasks of living. Institutionalised cisgenderism treats some people's genders and bodies as "out of the ordinary", while simultaneously treating their oppression as ordinary (see Namaste, 2005). I examine how cisgenderism in medical settings can affect people's daily lives *outside* of medical environments. I critique three components of medical systems that can perpetuate institutional cisgenderism: evidence-based medicine, feedback pathways, and consultations with community leaders. Next, I propose new ways to achieve genuine partnership between professionals and laypeople when designing medical systems and determining policies. I call this structural partnership *collaborative system co-authorship* because it involves professionals sharing with laypeople the power to *co-author* procedures, policies, care pathways, feedback mechanisms, and other institutional processes. After giving examples of these collaborative system partnerships, I pose questions to guide structural changes and challenge cisgenderism in medical settings.

Formal academic research is often ill-equipped to capture the kinds of information that I present here. The personal narratives that follow were not structured interviews conducted as part of my academic research, but informal data that have been gathered from multiple contexts on multiple continents and from multiple experiential roles beyond that of an academic researcher. I use this information here to illustrate some of the current gaps in formal research: "data" that I have been able to hear and see in these contexts are rarely captured in formal interviews, survey questionnaires, or outcomes assessment measures. This chapter challenges the idea that most formal research fully captures all relevant "evidence", provides a critique of how those "data" are omitted from academic research, and offers suggestions for how to address erasure and exclusion in research. All people who have been quoted here provided written permission to use their information, and all specific identifying details have been changed or composited as necessary to preserve their privacy.

“The System Wouldn’t Let Them”

Malik¹ describes himself as “a 31 year old British Pakistani man of trans experience in a medium sized English city”. When discussing his medical care during an informal conversation with me as a health advocate, Malik said:

I was having periodic abdominal pain and spotting for a few weeks last year. It had been several years since my last smear test, so I thought it would be a good idea to make sure there wasn't a problem. When I tried to make an appointment to have one, I was told that it wouldn't be possible, because my medical record lists me as male. After several minutes of insisting that it was *necessary*, the receptionist told me that the only way to do it was to change my record to female. If I hadn't been in so much discomfort, I would have just not done it, as I had in the past. I eventually agreed to her changing my record *temporarily*.

So, I had the test and got the results, but then they wouldn't change my record back to say male. They said that '*the system*' wouldn't let them and that I would need to be able to receive reminders to have my next routine smear. I started getting post addressed as 'Miss' and even pink smear reminder postcards. I was mortified, and the postman started giving me very strange looks. It didn't take long for my previously friendly neighbours to avoid me, and I was eventually getting harassed by local kids. I had to move to a new city to ensure that the rumours wouldn't catch up with me. My new doctor doesn't know my history. That kind of scares me, because I don't know what to do if I have a problem.

This misgendering system contrasted with the clinic’s official description as a “patient-centred” and “empowering” care facility. Written and verbal mispronouncing (Ansara, 2010) in medical communication constitutes serious ethical misconduct that violates medical privacy legislation and accreditation requirements. Some critiques of cisgenderism in medical settings focus on actions by individual professionals, who are assumed to have sole authority to set policy. Malik’s experience highlights the authority that medical systems exert over individual professionals.

Cisgenderist Structural Violence in Medical Settings

Malik’s experience with the receptionist is an example of *structural violence*—harm caused when societal structures and institutions deny people’s basic needs (Galtung, 1969). The term *structural* here describes how systemic inequalities are integrated into organisations and

institutions, and the term *violence* describes how these structural arrangements harm people (Farmer, Nizeye, Stulac, & Keshjavee, 2006). Since 1946, the World Health Organisation (WHO) has defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 2011). This definition of ‘health’ provides a useful frame for understanding structural violence.

Malik’s experience illustrates that “health care” can actually damage people’s health when medical systems engage in structural violence. Several people who contacted me for assistance in my health advocacy role shared personal narratives of having to relocate for similar reasons. Many told me they withhold clinically relevant information from medical professionals or avoid the social health risk of medical care altogether due to privacy concerns. Medical professionals seeking to improve people’s health often engage in this form of violence unwittingly. Even with individual good intentions and practices, structural violence can be very difficult to challenge. Structural violence is deeply ingrained in how our societal structures function, and normalised through institutional processes that are part of people’s regular experiences (Gilligan, 1997). This form of violence often becomes an invisible and integral aspect of how medical systems work.

Farmer et al. (2006) assert that structural violence can only be challenged effectively with *structural* interventions. Interventions to reduce cisgenderist structural violence must be informed by laypeople’s direct, personal knowledge of cisgenderism. This point becomes evident when we consider, “with few exceptions, clinicians are not trained to understand such social forces, nor are we trained to alter them. Yet it has long been clear that many medical and public health interventions will fail if we are unable to understand the social determinants of disease” (Farmer et al., 2006, p. 1686). Farmer et al. critique the desocialisation that occurs in medical contexts when health issues with biosocial components that include poverty and discrimination are treated as strictly biological. Thus, structural interventions must be informed by people’s own insights about how ostensibly biomedical interactions affect their physical, mental, and social well-being.

Authoritarianism in Medical Systems

Authoritarianism has been defined as the belief that purely personal needs and values should be subordinated to group requirements (Duckitt, 1990). Medical professionals are understandably uncomfortable with the notion that authoritarianism has anything to do with their own organisational

practices. Discomfort with this concept often stems from its association with right wing violence. Yet organisational strategies for assessing and improving lay people’s medical experiences typically contain elements of authoritarianism, and these forms of authoritarianism often inhibit successful structural interventions (e.g., Mayo, Hoggett, & Miller, 2007; Wilson & Kenkre, 2009).

Malik’s narrative reveals authoritarian elements in a nominally “patient-centred” clinic. Duckitt (1990) defined authoritarianism in terms of collective group *behaviour*. Medical systems often contain core elements of authoritarianism: *conventionalism*—when medical professionals promote and enforce conformity with social norms approved by established authorities, as when Malik was told that “the system” could not be altered to meet his needs; *authoritarian submission*—acquiescence to the sole authority of established authorities, as when the receptionist accepted “the system” that failed to meet Malik’s needs; and *authoritarian aggression*—hostility or coercion directed at people perceived as challenging authorities or social norms, as when Malik was told he would be denied necessary medical care unless he permitted the clinic to engage in the harmful act of misgendering him.

Mayo, Hoggett, and Miller (2007) discussed how external or centralised assessments often dismiss insights and experiences of individual professionals. Wilson and Kenkre (2009) identified how professionals’ own attempts to build communicative partnerships with laypeople can contrast with agency demands. In order to meet Malik’s needs, the receptionist and other colleagues would need to be empowered by the agency to make actual systemic improvements. Receptionists and front-line medical employees are rarely deemed competent to recommend or implement structural recommendations, even though these employees usually have far more direct exposure to laypeople’s concerns than practice managers or administrators. “Patient-centred” and “empowering” care cannot be achieved until those interacting with laypeople are allowed to make necessary structural adjustments.

“Evidence-Based” Medicine

“Evidence-based” has become a buzzword to describe medical approaches that are considered legitimate. “Evidence-based” interventions in clinical medicine address topics ranging from HIV prevention to substance use, from cancer treatment to young people’s emotions. Sackett et al. (1996) defined evidence-based medicine as:

the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical expertise we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice. Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care (p. 71).

Medical professionals whom I consulted when writing this chapter confirmed that this definition accurately reflects their understanding of “evidence-based medicine” today. This medical decision-making model overestimates medical professionals’ ability to identify people’s predicaments and preferences accurately from information gained during clinical encounters. Evidence-based medicine authorises professionals to speak on behalf of laypeople. As one retired health professional stated when we discussed problems with this medical model, “in the vast majority of cases, we do not speak for patients and cannot ethically (or objectively) substitute our judgment for theirs. Authoritarianism among professionals is a form of structural violence (which is not excused by being somehow well-intentioned).” Alexis, who describes herself as a “24 year old white, class-privileged, queer trans femme from Sydney,” Australia, exchanged private, text-based communications with me about her experiences, based on my health care advocacy and activist roles. During our communications, Alexis shared a common experience of feeling that her own knowledge would not count as “evidence” during clinical decision-making about her endocrine care:

omg progesterone SUX!!! i took ALL the different kinds and they still fucked me up. i don't bother taking it anymore and i'm really happy. i've read a bit and heaps of trans women don't take it. but i've also heard from other trans women that if you go to a compounder and get natural progesterone it doesn't have the mental health impacts. (and i don't bother telling my endo i'm not taking it, i just say it's going fine and he writes me a script i don't ever fill).

Professionals have often responded to discovery of laypeople’s inaccurate or incomplete disclosures by advocating measures to ensure “truthful” communication. This response ignores systemic power imbalances that close off avenues for laypeople’s empowered communication in medical settings, thus leaving them with few options other than Alexis’s

strategy of creative information management. Medical professionals typically have poorer communication with people from historically disadvantaged populations, and poor communication between medical professionals and laypeople contributes far more to health disparities than patient preferences or professional prejudices (Ashton et al., 2003). Medical systems perpetuate health disparities by failing to provide mandatory training in communication skills with people affected by cisgenderism. In the context of medical systems that often disregard laypeople's insights, clinicians must actively encourage laypeople to collaborate or risk missing information necessary for quality care.

When professionals failed to provide useful information, Alexis relied upon evidence from other laypeople about how to avoid negative mental health effects from progesterone. Many professionals who rely on evidence-based medicine have no exposure to these channels of information shared among laypeople, and thus are unable to consider this information during clinical decision-making processes. Even highly experienced medical professionals specialising in "trans medicine" can miss this vital clinical knowledge when gathering "evidence". Training in cisgenderism-aware medical interviewing techniques is likely to result in more fully informed clinical judgements and intervention strategies.

Sackett et al. (1996) note that definitions of "evidence-based medicine" continue to evolve and adapt, suggesting that new interpretations have the potential to improve the quality of what is considered evidence. Some researchers have recognised that the concept of "evidence" itself is constructed rather than neutral. Messing, Schoenberg and Stephens (1983) described how ideology can influence all aspects of the research process, including how research questions are framed, how studies are designed, and how results are interpreted. Similarly, Spanier (1995) has shown how gender ideologies influence descriptions and interpretations of "evidence" in molecular biology.

Clinical interventions are often based on discriminatory ideology cast as "evidence". Ansara and Hegarty's (2011) quantitative content analysis of pathologising and misgendering forms of cisgenderism in psychological literature on children's gender and expression, published from 1999 to 2008 inclusive, found that cisgenderism had remained stable; that mental health professionals were more cisgenderist than authors in non-mental health professions; and that articles by members of an 'invisible college' structured around the most prolific author in this research field were more cisgenderist and had higher impact than other articles. These cisgenderist research findings often determine medical approaches to young people

with self-designated genders. Ansara and Hegarty described three decades of research in the pathologising field of “gender identity disorder” (sic):

research has been predominantly limited to children seen only in clinical contexts wherein children’s definitions of themselves have been effectively erased. This erasure persists despite recent findings from researchers using participatory methods that children can be knowledgeable and competent co-researchers whose own experiences, perceptions and social agency are often necessary for successful health interventions (p. 15).

“Evidence-based” medicine typically relies on these strictly clinical accounts from the perspectives of health care professionals. These accounts omit lay people’s own insights about how existing structures can thwart their health needs.

The World Professional Association for Trans Health (WPATH) is “a professional organization devoted to the understanding and treatment of *gender identity disorders*” (sic) aiming “to promote *evidence based* care, education, research, advocacy, public policy and respect in transgender health” (WPATH, 2011a, emphasis added). WPATH aspires to guide health care practices and research around the world through its Standards of Care (SOC) (WPATH, 2011b). In the past, these “standards” have determined whose information counts as “evidence”; many people around the world have been denied access to hormones and surgery when their genders and bodies did not conform to WPATH-endorsed psychomedical ideology. On September 25th, 2011, WPATH published the first new SOC since 2001. I discussed his individual view of the new SOC7 with WPATH Board Member Sam Winter, who noted that “the new SOC represent a major shift in the work of trans healthcare providers: from raising barriers to extending services; from one-size-fits-all healthcare to meeting individual needs; and from treating disorder to embracing difference” (personal communication). These SOC begin to address multiple structural problems in WPATH. SOC7 is also the first version to state explicitly that attempting to change young people’s self-designated genders to match their assigned genders is unethical.

Numerous problems remain. SOC7 states that psychotherapy should not be required for people who are labelled “transgender” or “gender variant” to access medical resources for gender affirmation, while recommending psychological assessment before providing these resources to people whose bodies are not strictly male or female. SOC7 further embodies cisgenderist ideology when stating that “it is advisable for patients with a DSD to undergo a full social transition to another gender role only if there is a long-standing history of *gender-atypical behavior*”

(p. 71, emphasis added). WPATH's International *Journal of Transgenderism* routinely publishes highly cisgenderist articles that violate both the spirit of SOC7 and American Psychological Association publication guidelines for reducing bias in language (APA, 2010). SOC7 may consider attempts to change young people's self-designated genders unethical, but current WPATH leadership includes several highly cisgenderist professionals linked to this unethical practice (see Ansara & Hegarty, 2011, p. 12; Winters, 2008).

SOC7 also perpetuates cisgenderism by explicitly rejecting non-pathologising language like "intersex", which is the current preferred terminology among people being described by this language. SOC7 even claims that WPATH's use of pathologising "Disorders of Sex Development" (DSD) terminology to which "some people object strongly" (p. 69) is "objective and value-free" (p. 69). Citing a misnamed consensus document from which dissenting professionals and activists were excluded, SOC7 states that "the terminology was changed" (p. 69). This account ignores and silences extensive evidence from the many laypeople and health professionals who continue to reject "DSD" (WPATH, 2011b). Far from "embracing difference", "DSD" terminology has been used to promote harmful and medically unnecessary infant genital surgeries that violate human rights described in the Yogyakarta Principles (International Commission of Jurists, 2007) and the UN Convention on the Rights of the Child (UNCRC, 1989). To fulfill the aims Sam Winter described, WPATH will need to make significant structural and policy changes that challenge institutional cisgenderism.

Medical systems authorise professional researchers to determine which information counts as "data" and which will be dismissed as mere anecdotes. Cisgenderist erasure can occur when researchers apply these methodological assumptions uncritically. Consider "outliers", people whose data are excluded from statistical analysis because they are considered too "out of the ordinary". This practice can perpetuate erasure of people affected by cisgenderism. For example, one researcher told me that her study had multiple respondents who wrote non-binary gender categories on a demographic questionnaire. Instead of altering her analysis and future coding system to match the variety of actual participant data, this researcher informed me that she would be removing all of these respondents as "outliers".

Dismissive medical approaches to "outliers" can lead to health disparities. Clinical studies of congenital adrenal hyperplasia (CAH) typically exclude people who identify as men or boys, assuming that all people with CAH self-designate as women and are raised as girls. Health

research and social support resources for people with CAH systematically exclude these men and boys. As a result, many do not receive adequate medical monitoring for serious medical complications common among people with CAH. Similarly, screenings for testicular, breast, cervical, and prostate cancer are gendered by cisgenderist policies that assume people's genders and bodies match up in particular ways.

I served for several years as director of Lifelines/Cuerdas de Salvamento, a non-profit organisation focused on the needs of people affected by cisgenderism. As a medical advocate, I frequently accompanied our constituents to medical appointments. During one such visit, the layperson who had requested my presence counted six times that he had been misgendered by medical staff before he had even met the endocrinologist with whom he had scheduled his appointment. He asked me to share his discomfort with the specialist, since he felt “shut down” by medical staff in a supposedly safe place. The endocrinologist responded briskly, “Well, what do you expect? Only five percent of our patients are trans anyway!”

Feedback Pathways

Feedback forms are among the most widely used measures to assess people's experiences in medical settings (Evans, Edwards, Evans, Elwyn, & Elwyn, 2007). The experience of Matt, who describes himself as, “a 19 year old white British man from southeast England”, illustrates how existing feedback systems conceal structural violence:

About four years ago, I decided that transitioning was the way forward for me, that I was male, and that I needed my body to be aligned with that. I spent about a year and a half considering the process of transition, making sure I understood the ramifications of the decision I was making, and that I was ready to make these changes to my body. I felt by that point I'd completed the vast majority of 'emotional work' necessary to transition, and was prepared to embark on the physical process.

Following the referral procedure I'd read online (my GP had no idea what to do), I went to the local mental health team, and asked for a referral to a gender identity clinic. The local team decided therapy was the way forward, and I spent about six months discussing my gender over and over with them, “yes it's still the same, yes I'm still a boy...” Being under eighteen, my only option was the Portman and Tavistock – the only clinic in England that deals with 'gender identity disorder' in children and adolescents. However, since by that point I was 17, there was little reason for me to be referred there – funding and appointments take so long to

arrange that they might only have managed to see me once before I turned 18.

I hung on another year, constantly attempting to persuade them to write a referral to Charing Cross Gender Identity Clinic, where adult services are located. During that time I got increasingly depressed, moved onto antidepressants, and started on depo provera, which is progesterone based, to stop my periods while I waited for testosterone. Well it did stop my periods, but it also changed my boyish androgynous figure into an hourglass worthy of a Victorian lady. When I turned 18, surely it would be time for my referral to be sent?

No, another 4 months of waffling before my referral was finally sent off. It took me over a year to get an appointment. I begged to be able to start university on hormones. No chance.

I looked into private treatment, but since I'd been offered an NHS appointment, the private clinic wouldn't see me. By then I'd been living as male for two years, my name was changed, and I really just needed hormones to help me be better 'read' by society as male. The first appointment was an hour of talking, and I had to get blood tests and wait another 4 months for an appointment with a different doctor, who looked at my blood tests, all the results in the normal female range, and decided that since my testosterone levels were at the high end of the female range, I had to see an endocrinologist as well. Thankfully that went well, and I started hormones in February 2011, 3 full years after trying to take that step.

Now the journey to chest surgery has begun. In all likelihood I'll have to wait another year from now before that can happen, bringing it to four and a half years of waiting. And phalloplasty? God knows when *the system* will let me have that (emphasis added).

The systemic delays Matt faced had an impact beyond the medical settings in which they occurred, interfering with his entry to university, his social life, his body, and his mental well-being. Matt would have liked the opportunity to share negative aspects of his medical care with the gender clinic. His critical feedback was silenced by the design of the feedback pathway:

Once at Charing Cross Gender Identity Clinic, I was able to give feedback on five points. I remember one of them was the quality of the reception service, and I remember one of them was to do with how involved you feel in the decision process about your treatment, but for all of them, all you can do is mark it on a scale of good to poor.

I just marked it all as acceptable, since *within the bounds of what the staff were allowed to do*, I got through everything quite effectively. I felt marking stuff as poor would reflect badly on the staff, which wasn't what I wanted. The electronic feedback machine was missing the ability to add detail, to express my discontent with the process itself. (emphasis added).

Organisations often assume that lack of objection means satisfaction. Matt's example is a reminder that feedback pathways rely on *solicited* feedback limited by the unequal power relation between people's critical insights and the authority of medical hierarchies to determine which of these insights can be expressed through official feedback pathways.

A community health centre in the United States responded to numerous complaints about insensitive medical professionals by creating a separate care pathway for people with self-designated genders. Newcomers were directed to a "trans health navigator" who was responsible for ensuring a positive experience at the clinic. While benevolent aims motivated the "system navigator" approach, some laypeople resented what they experienced as an invasion of their privacy or the imposition of 'trans mental health' services that they found unhelpful and unnecessary. Others were disappointed that medical professionals at the health centre continued to use misgendering terminology to describe their intimate anatomy. Many sensed that the system navigator's job was intended more to manage their complaints than to effect meaningful change to the system being navigated. Several people expressed anger when their complaints to the system navigator were met with apologetics rather than structural intervention. This clinic's status as an emerging "best practices model for trans health" suggests widespread ignorance about these problems.

During one of my patient advocacy visits, I accompanied Tom, a man with a self-designated gender, to his medical appointment at this clinic. Tom noted his discomfort with the general practitioner whom he was told "sees all the trans patients", because this practitioner was a woman and Tom prefers to be examined by another man. After significant effort, he was granted an appointment with a man on staff as a physician's assistant. The separate pathway for people with self-designated genders meant that most of the clinical professionals had little knowledge of how to conduct a physical examination appropriately with "trans patients". This clinician remarked about the size and shape of Tom's genitals "compared to *normal parts*" (emphasis added), and described Tom using terms culturally associated with women's bodies (e.g., breasts, vagina, clitoris, labia). While some men prefer these terms, Tom clearly stated that he wanted his chest, cock, and frontal opening referred to in that manner. He found this examination traumatic. When the physician's assistant rebuffed Tom's

clear statements about his preferred anatomical terminology, Tom expressed resentment about being denied the authority to determine how his own body was described. The physician's assistant excused his behaviour based on his lack of familiarity with "bodies like yours", a deficiency enabled by the exclusion of 'trans patients' from regular medical pathways. Failure to provide laypeople with effective feedback pathways keeps health systems from being able to identify people's unanticipated needs and make informed structural improvements. Marking people with self-designated genders as "out of the ordinary" while excusing and enabling professionals' inadequacies perpetuates systemic inequities.

Tong prefers not to be referred to using men's or women's pronouns, preferring to be referred to simply as Tong. Tong identifies as "a Vietnamese refugee from Thailand who is third gender and a traditional healer". Despite Tong's status as a medical professional, Tong experienced problems obtaining basic medical care as a layperson from the moment Tong was asked to complete the intake questionnaire:

I had to put down all this stuff about male or female or transgender. I didn't put transgender, because it doesn't fit me. The nurses assumed that I am female. Then when the doctor saw me, she decided I am male. I am known for sticking up for myself, but I felt silenced by the system. How can I tell them, 'I am me, Tong, I am not a male or female or transgender?' I tried to tell one of the nurses, and he started laughing as if he was nervous.

This clinic had no existing feedback pathway to address exclusionary documentation, and Tong's attempt to provide this feedback was met with nervous laughter rather than changes to the intake questionnaire. Tong's feedback is important because it reminds medical professionals that quality care requires ongoing attention to seemingly mundane details: how medical forms are designed; which categories are acknowledged or excluded; which words are used to address new people upon first meeting; and which assumptions are made about people's anatomy based on their perceived or actual gender. Tong's feedback also illustrates how imposing culturally and linguistically specific terms like "transgender" can enact ethnocentric erasure (see also Namaste, 2000). Different people use words differently, and allowing people to self-designate ensures that clinical practice is informed by accurate information. As Tong's narrative demonstrates, gender cannot be determined merely by evaluating people's visual presentations or by using predetermined categories. Quality care must acknowledge cultural, geographical, and linguistic diversity instead of assuming that all people with self-designated genders have a 'trans'

identity or even that the constructs ‘trans’ and “identity” are universally valid.

Consultations with “Community Leaders”

Mea, who describes herself as, “a Khmer and Black immigrant trans woman”, recalls her disappointment with community leaders who organised a national trans community gathering in a large city:

I found out that the event was going to be held at the police headquarters. Now a lot of us in the trans people of colour communities have been harassed by police or know people who have been beaten up or threatened with deportation. The thing is that the police building, to get in there to where the event was going to be, you need to go through a metal detector and show your ID. Now you imagine how many trans people of colour want to show ID or go through a body scan. I mean, a lot of trans people have the wrong gender on their IDs anyway, even if they haven’t experienced racism from police. I knew a lot of people who didn’t feel safe going to this event. A friend of mine called one of the organisers to tell her how worried many trans people of colour were feeling and ask her to change the venue. Well, of course all of the organisers were white. This woman told my friend, “you aren’t the target population anyway”. So I guess we’re not part of ‘the trans community’ after all!

Some organisations elect trans activists and medical professionals with self-designated genders to serve in key policy-making roles, Unfortunately, these trans leaders and professionals are typically white, middle class, literate, and university-educated; they are rarely recruited from the most marginalised populations (Namaste, 2000). They are often as unfamiliar as other medical professionals with the experiences of people from diverse backgrounds whom they claim to represent. This ignorance often leads ‘trans community leaders’ to promote structural violence, as when ‘trans leaders’ at a community health centre embraced a proposal that would deny approval for genital surgeries to people living with HIV. In the course of my efforts to build contacts with local health-related organisations as a non-profit organisation director, people often shared troubling insights with me about the practice of consulting community leaders. During one such private conversation, a public health manager told me that he had been present at meetings at which several prominent trans community leaders consulting with officials from the regional health department had advocated denying hormones to anyone who did not identify as strictly a woman or man. Another health educator expressed shock when she heard several trans leaders at a senior-level policy meeting

tell medical administrators they should restrict access to hormone blockers and hormones for anyone under 18. When ‘trans leaders’ endorse these exclusionary and discriminatory approaches, they harm far more people than they help.

Most people harmed by cisgenderism are neither medical professionals nor activists. For the vast majority, living their lives “is not about challenging the binary sex/gender system, it is not about making a critical intervention every waking second of the day, it is not about starting the Gender Revolution” (Namaste, 2005, p. 20). Most do not consider themselves part of a community organised around their gender histories or bodies. Christine Burns, an internationally recognised Equality and Diversity professional who chaired a Department of Health committee on ‘trans health issues’ in the UK, documented how listening to people’s concerns in their own words can improve structural problems (personal communication, 31st August, 2011). *There is no substitute for listening to people’s own experiences in their own language.*

From Authoritarianism to Collaborative System Co-Authorship

Undoing cisgenderist structural violence means recognising that “the same normative valuation on impersonal, generalized rules that defines bureaucracies and makes them powerful in modern life can make them unresponsive to their environments, obsessed with their own rules at the expense of primary missions, and ultimately lead to inefficient, self-defeating behaviour” (Barnett & Finnemore, 1999, p. 699-700). If we want responsive medical systems that promote health across all domains of people’s lives, we need to encourage people affected by cisgenderism to *co-author* these systems in collaborative partnership with medical professionals. Every single medical encounter must be recognised as an opportunity for structural change. Each interaction can contribute to reducing institutional cisgenderism.

I have witnessed the powerful change these partnerships can effect. One community health clinic changed their forms when they realised that people were omitting key medical information due to the gendered nature of existing questionnaires (e.g., “if you are a woman, when was your last period?”, which overlooked many women who had never experienced menstruation and many men who did). One clinic created an anonymous, online feedback form; anonymous feedback led administrators to insist that their medical lab process test results without changing gender markers on people’s medical records. One specialist connected people with our

peer support group when she recognised that she lacked knowledge shared among laypeople. Medical professionals Jody Rich³ and Norm Spack⁴ collaborated with me on a grand round at which I shared laypeople's direct personal narratives with several hundred medical professionals and students in continuing medical education accredited by the American Medical Association. Our collaborative partnership led numerous professionals to transform their practices. Several contacted me to convey how the presentation would inform future clinical decisions.

Seven Reflective Questions for Medical Professionals

Collaborative processes can quickly shift to reinforce existing hierarchies when professionals cease to interrogate their own assumptions and practices. Guidelines and standards of care that impose rigid and static rules are poor substitutes for critical thinking and empathic listening. Health professionals and organisations must continually question their practices and change ill-fitting policies. Initial questions will often lead to questions of greater depth and understanding rather than static answers; additional questions must be generated in collaborative dialogue between laypeople and professionals. I invite readers to initiate these partnerships with the following questions:

- What assumptions do I have about the laypeople involved in my research or clinical practice, and how can I seek critical feedback from them about these assumptions?
- Whose information and experiences are missing from my definition of evidence, and how can I include laypeople's varied experiences and knowledge in my evidence-based practice?
- Have I sourced laypeople beyond activists or community leaders when asking health policy questions, including people with non-binary self-designated genders and people whose bodies are not strictly male or female?
- Have I created safe and accessible environments in which non-activist laypeople can communicate their views about health systems on their own terms and in their own languages?
- Are these communication pathways equally accessible for people who may be Deaf, visually impaired, non-literate, night shift workers, undocumented immigrants, single parents, of limited

physical mobility, rural, speakers of other languages, people whose voices and visual appearances are likely to be misgendered, reliant on public transport, and people who do not have private space in which to access phone or internet resources?

- Have I consulted people in health systems and cultures that differ markedly from my own regarding how my health policy or standard of care might affect them?
- Have I asked laypeople from diverse demographics about possible structural inequities that my policy or standard might perpetuate or create?

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Notes

- 1 Pseudonyms have been used for personal narratives.
- 2 Josiah D. Rich is a Professor of Medicine and Community Health at Brown Medical School, Attending Physician at The Miriam Hospital, and Director and co-founder of The Center for Prisoner Health and Human Rights at The Miriam Hospital Immunology Center.
- 3 Norman Spack is a paediatric endocrinologist at Children's Hospital in Boston, founder of the Gender Management Service (GeMS) Clinic, and Associate Professor of Paediatrics at Harvard Medical School.

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